Division of Extramural Activities

Director's Consumer Liaison Group

Regular Meeting Minutes
April 19-20, 1999

The second meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) as a chartered committee convened at 8:30 a.m. on Monday, April 19, 1999 at the Natcher Conference Center, Bethesda, Maryland.

DCLG MEMBERS

Paula E. Bowen
Susan Lowell Butler
Manuel H. Castillo
Kerry J. Dewey
M. Venus Ginés
Felicia Schanche Hodge
Michael Katz.Susan A. Leigh
Ruth Chiang Lin
Gena H. Love
Daniel M. Moore
Lillouise Rogers
Susan K. Stewart
Brad Zebrack

NCI OFFICE OF LIAISON ACTIVITIES STAFF

Eleanor Nealon (Executive Secretary, DCLG)
Elaine Lee
Maria Stamos
Kristie Dionne
Sabrina Ferguson
Tracy Kilmer

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OPENING REMARKS

Mr. Katz welcomed everyone present and noted that this was a transitional meeting for the DCLG as for the first time DCLG members would be the primary presenters of information rather than an audience for presentations by others.

DIRECTOR'S REPORT

Dr. Klausner said he was very appreciative of the work DCLG members had done in the first phase of the communications feedback initiative. He added that the DCLG plays an enormously important role as a group that is able to inform NCI about how it is perceived by

the outside world.

New NCI Funding Initiatives

Dr. Klausner noted that NCI's primary role is to provide the infrastructure for cancer research that is conducted nationwide. Most NCI planning is concerned with establishing and maintaining programs that permit a broad range of cancer research to be carried out (e.g., cancer centers, cancer control and prevention, drug discovery, clinical trials). Two years ago NCI began a process of examining how to best use the infrastructure that is in place to make progress against specific types of cancer. The first phase of this process produced the reports of the breast and prostate cancer progress review groups (PRGs). Lessons learned to date from this process include the following:

- Similar needs were identified and actions recommended for both diseases.
- Many of the priorities identified for each of these cancers can be addressed through programs that exist or are planned.

In response to the PRG recommendations NCI created 20-30 new initiatives through which most of the reports' goals (as well as many of the goals for other cancers that have not yet been through the PRG process) could be realized. Achievement of these goals, however, requires resources, awareness that the initiatives exist, and action by the research community. NCI is now engaged in a communications effort to inform the research community about these new initiatives through advertisements and announcements in journals, meetings with professional societies and advocacy groups, presentations at scientific meetings, etc. Additionally, all of the initiatives are listed on NCI's website. NCI is also developing a "kit" that is intended to simplify and speed up the process of conducting future PRGs.

Another result of the PRGs has been a reorganization of NCI's research portfolio according to the scientific questions being addressed. NCI developed a Common Scientific Outline (CSO) that was pilot-tested by the Department of Defense and will be used by them and the American Cancer Society. This should lead to better coordination of cancer research programs. NCI is also developing a catalog of all of its technical and other resources to aid researchers.

Dr. Klausner made the following comments in response to questions from DCLG members.

- NCI support overwhelmingly goes to researchers in the United States. However, NCI is actively involved in partnerships with researchers in Europe, Africa, and Central America and is exploring ways to increase interactions with Latin America and Asia.
- The fact that applications for NCI grant support have increased 27% this year suggests that the research community is becoming informed about and is responding to the institute's new initiatives. However, communication with researchers can still be improved. One of the goals of the redesign of NCI's website is to make it easier for researchers to obtain the information they need about NCI resources and programs.
- He welcomes the opportunity to work with the DCLG to develop approaches to informing advocacy organizations and their affiliated scientific groups about NCI's new initiatives.

NCI Response ot Institute of Medicine Report *The Unequal Burden of Cancer*

Dr. Klausner said that this report identified important issues, many of which NCI is already

making efforts to address. NCI's formal response to the report will be provided to DCLG members as soon as it is available. Dr. Klausner made the following comments on specific issues raised in the Institute of Medicine (IOM) report:

- Surveillance. He agreed with the IOM committee's recommendations and offered to provide DCLG members with a report prepared by NCI's Surveillance Implementation Group, which makes similar recommendations regarding the enhancement of cancer surveillance efforts. An explicit plan will be presented soon to expand surveillance of Hispanic, Native American, and rural populations. An evaluation of surveillance of migrant farm worker populations is under way. Also in development is a cancer "report card" that will provide a richer picture of the burden of cancer.
- **Underserved populations.** He agreed with the IOM committee's recommendation concerning the need to develop a flexible, workable definition of the underserved, noting that NCI will be convening a workshop on this issue.
- **Coding.** There is a large discrepancy between the IOM committee's and NCI's own estimates of the level of NCI spending for special populations. The National Cancer Advisory Board appointed a subcommittee to look at NCI's coding process and suggest changes.
- **Special populations.** NCI established a working group to coordinate its special populations activities and to serve as a link with organizations representing those populations. An expanded research and outreach program, the Special Populations Network, which replaces the previous Leadership Initiatives, will serve all special populations instead of focusing on certain subgroups. Rather than setting up separate programs and planning processes for special populations concerns, NCI is raising awareness of issues related to special populations in all of its programs and planning processes. A centralized listing of all of the special populations initiatives that are under way across NCI is available on the web and a pamphlet will soon be available.

NCI 2001 Bypass Budget: Extraordinary Opportunity in Cancer Communications

Dr. Klausner announced that the new Bypass Budget will include three new Extraordinary Opportunities: cancer communications (proposed by the DCLG and other entities), tobacco, and molecular targets. He noted that "cancer communications" meets all the NCI criteria defining an Extraordinary Opportunity, and, thanked the DCLG for its initiative in putting the proposal forward.

General Discussion

Several issues of special interest to DCLG members were raised with Dr. Klausner. Mr. Zebrack suggested that the review process for grant applications should define criteria for the inclusion of special and underserved populations in studies more stringently to include evidence of ability to recruit these patients. Dr. Klausner agreed and urged DCLG members who have participated in peer review panels to submit comments and recommendations concerning review criteria to NCI's Division of Extramural Activities (DEA). To ensure that comments from DCLG members are acknowledged and considered, copies should be sent to the Executive Secretary of the DCLG.

Ms. Stewart commented that, in her experience, clinicians often did not know how to recruit special populations or felt that they did not get credit for making the effort. Dr. Klausner replied that $1.1 million of the clinical trials budget was set aside last year to provide

assistance in recruiting special populations. He added that although recruitment of minorities into treatment trials is now proportional to their disease burden, greater efforts are needed to recruit minorities into prevention trials.

In response to a question by Mr. Katz, Dr. Klausner said that the President has requested a 2.4% increase in NCI's budget for fiscal year 2000. An increase of this magnitude would allow NCI to continue current programs but to initiate very little.

In response to a question by Dr. Castillo, Dr. Klausner said that economic considerations, including lack of insurance and the cost of travel, do present barriers to clinical trial participation by minorities and poor people. NCI is taking steps to expand access to clinical trials as much as possible. Although it is beyond NCI's mission to cover patient costs in clinical trials, the Institute is working with third party payers to cover these costs and supporting research to identify costs incurred through trials.

DIVERSITY ISSUES (Venus Ginés)

Ms. Ginés said that she represented the Latino community at an IOM meeting last summer at which testimony was presented relating to the unequal burden of cancer. One of her recommendations was that NCI increase its visibility by becoming more involved in activities at the community level. She questioned whether research adequately addressed behavioral and cultural risk factors for cancer in the Latino population. She presented data demonstrating that a culturally appropriate outreach program had succeeded in increasing Latina participation in mammography screening. She advocated greater partnering with community organizations and more grant-writing assistance for community groups.

COMMUNICATIONS EXTRAORDINARY OPPORTUNITY

Mr. Bernard Glassman, an informatics expert, reviewed the timeline for preparing the 2001 Bypass Budget, which will be submitted to the President in September 1999. He explained that the rationale for the selection of cancer communications as an Extraordinary Opportunity, is based on the current revolution in communications technologies, especially wireless technologies, which offer powerful new ways of using health communications to reduce disease risk, incidence, morbidity, and mortality, as well as to improve quality of life. Explosive growth in the use of the Internet has created both an opportunity and a need to make high-quality, reliable and easily understood information widely available to diverse audiences. One example of how new technologies are being used was demonstrated. Mr. Glassman showed a video clip about a computer-based personal health support system called CHESS (Comprehensive Health Enhancement Support System), a University of Wisconsin - Madison pilot project. Using CHESS in their homes, patients could obtain referrals, read journal articles, consult a dictionary of medical terms, and (the most heavily used feature) participate in online discussion groups led by a trained facilitator.

Goals of the Extraordinary Opportunity in cancer communications include the following:

- Accelerate the reduction in the U.S. cancer burden through the use of cancer communications.
- Increase the demand for, access to, and use of cancer communications by the public, patients, high-risk individuals, underserved people, cancer survivors, and health professionals.

- Use cancer communications to speed the dissemination of "best practices" in cancer prevention, research, and survivorship.
- Develop an infrastructure for rapid advances in knowledge of cancer communications and dissemination of results to researchers, clinicians, patients, and advocacy groups.

Specific actions to be carried out include:

- Expand data collection and interdisciplinary research.
- Create cancer communications centers of excellence.
- Develop practical tools for the dissemination of cancer communications, including "toolkits" for the public, patients, underserved populations, advocates, the media, and health professionals.
- Enhance partnerships with academia and industry as well as with other Federal agencies (Centers for Disease Control and Prevention, other NIH institutes).

Although the Bypass Budget is still in preparation, Requests for Applications (RFAs) associated with the cancer communications Extraordinary Opportunity are already being drafted. Mr. Katz said he would like to see DCLG involvement at an early stage in the process of developing RFAs.

Mr. Glassman also described coNCIerge, a Web tool that creates hyperlinks on health-related words, which link to an NCI glossary. Eventually it will also link to other related information, such as incidence and mortality data and information about clinical trials. This tool will be integrated into the redesigned PDQ and CancerNet. With coNCIerge turned on, the user will be able to link to NCI information from any Internet site. Mr. Glassman predicted that in the future Web browsers will be upgraded so that any user is "one click away" from reliable cancer information.

With regard to NCI's current use of multiple glossaries of medical terms, Ms. Susan Hubbard, director of the Office of Cancer Information, Communication, and Education (OCICE), said that a project is under way to create one consolidated NCI glossary.

COMMUNICATIONS INITIATIVE

Introduction

Mr. Katz said that as part of NCI's efforts to improve cancer communications, Dr. Klausner asked the DCLG to provide feedback and recommendations on NCI's current cancer communications initiatives. The first phase of this effort was conducted over a 6-week period immediately prior to this meeting, and the reports being presented are still in draft form. The report will describe how people outside NCI see the Institute. It will be a first look at this kind of feedback which is not a formal scientific inquiry. This meeting will engage the full DCLG in discussion of the initiatives.

Feedback gathered from consumers and advocates is based on past experiences with NCI communications programs. However, the communications programs that are the focus of this effort are in a state of flux. Upgrades, improvements, and redesigns are already under way to address a number of the issues identified in the DCLG's review. NCI's website was excluded from the initial review cycle, although issues relating to the website were raised in the context

of initiatives being reviewed. The website will be reviewed at a later date.

During this phase, the DCLG teams who reviewed specific communications initiatives are:

- **Physician Data Query (PDQ):** Susan Leigh (team leader), Manuel Castillo, Venus Ginés, Ruth Lin
- **Cancer Information Service (CIS):** Felicia Hodge (team leader), Paula Bowen, Gena Love, Lillouise Rogers
- **Office of Cancer Communications (OCC):** Susan Butler (team leader), Kerry Dewey, Michael Katz
- **Clinical Trials Promotion (Intramural and Extramural):** Susan Stewart (team leader), Daniel Moore, Brad Zebrack

The DCLG developed processes to collect feedback from consumers advocates through websites and other mechanisms including personal interviews. Feedback forms about contacts with NCI were developed and placed on the websites of the International Myeloma Foundation and the Association of Cancer Online Resources (ACOR). Team members were encouraged to use ACOR email groups, as well as their contacts in the consumer advocacy organizations in which they are active, to solicit feedback about knowledge and usefulness of NCI resources and information. A total of about 420 responses were received, including 180 sent via the Web, 80 sent by email, and 160 sent in hard copy. Although this was not a scientific study and the respondents are not a random sample, the responses present a snapshot of "real world" experience with, and perceptions of NCI communications programs. For example, among Web and email respondents, 66% had heard of PDQ and 52% had used it; 66% had heard of CIS and 34% had called. Respondents related both disappointments and positive feedback regarding these contacts with NCI and made many suggestions for improvements in NCI services.

Office of Cancer Information, Communication, and Education (OCICE)

PDQ **(Susan Leigh, team leader)**

PDQ, NCI's comprehensive clinical cancer database, contains peer-reviewed summaries on subjects including cancer treatment, screening, prevention, and supportive care; a registry of cancer clinical trials around the world; and directories of physicians, genetic counselors, and cancer-care organizations. PDQ is accessed primarily through the CancerNet® and cancerTrials® websites and through the NCI Information Associates Program. Information is also provided through CancerFax® and CancerMail®.

At the beginning of the review, one team was originally assigned to review both PDQ and the Patient Education Branch. However, due to time constraints, the patient education programs will not be reviewed in this round.

Reasons respondents gave for using PDQ included obtaining information about their own illness, about treatment options, and (frequently) obtaining information to formulate questions to ask their doctor. Although many respondents said that PDQ information was easy to read and understand, some felt that insufficient technical detail was included while others commented that the information contained too many technical terms. Some respondents noted that the information was outdated.

Most, but not all, respondents who used PDQ found the service through the Internet. However, searches with a variety of World Wide Web search engines found that PDQ and NCI resources in general are not prominent on the Web. A discussion ensued about how to improve linkages between NCI's website and the websites of cancer advocacy organizations. Ms. Hubbard, whose office is responsible for PDQ, said that better linkages are being sought as the PDQ redesign continues.

PDQ's use of an advanced technology platform was considered both a strength and a weakness. The database is accessible to anyone with the resources and skills to use a personal computer, but inaccessible to others. Another limitation is the lack of culturally appropriate information in languages other than English. Maintaining the currency of massive amounts of scientific information was recognized as a major challenge.

Recommendations for PDQ include:

- Incorporate a hyper-linked glossary into the PDQ website so that users can quickly look up unfamiliar terms.
- Find alternative terminology to replace the designation of information as "for patients" or "for professionals" to reflect the technical level of information under each link.
- Rename PDQ to better reflect the fact that it is a service for patients and consumers as well as for health professionals.

CIS **(Felicia Hodge, team leader)**

The CIS handles about 600,000 telephone calls per year, over 75% of them from cancer patients and their families; 48,000 callers are specifically inquiring about clinical trials. Ms. Chris Thomsen, CIS chief, said that CIS information specialists use PDQ as a basic resource.

Most respondents who contacted the CIS had done so to obtain information about a specific type of cancer. Features that respondents said they liked about the CIS included: information was available at no charge, publications arrived quickly, and information specialists spent time answering their questions. However, some reported unhelpful information specialists, long waits on hold to speak to an information specialist, and receiving outdated or inappropriate information.

Identified strengths of the CIS included: availability at no cost via a toll-free telephone number (1-800-4CANCER); provision of general information, referrals, and a wide variety of publications; outreach to hard-to-reach populations; and ongoing evaluation of services. Weaknesses included lack of availability to people without a telephone and inconsistent relevance and sensitivity to diverse cultures.

Ms. Thomsen said that in addition to providing information, the CIS also conducts research, working with investigators to find better communication strategies and more effective interventions to change behavior. One current research project is testing whether behavior change occurs if information provided is tailored to a caller's needs.

Ms. Thomsen also addressed the issue of confusion within the advocacy community over the number of copies of publications that may be obtained from the CIS. She said that it is difficult for the CIS to maintain adequate supplies of extremely popular publications. When publications are being reprinted, it is sometimes necessary to limit the number that can be

supplied per month to any organization. She said that she would be happy to work with DCLG members to ensure that their publication requests were met.

In regard to evaluation of the effectiveness of CIS activities, Ms. Thomsen said that some efforts have been made to measure the penetration of CIS-efforts but that it is a major challenge to evaluate how many people have been reached by the CIS through its 4,500 community partners.

Recommendations for the CIS included:

- Conduct focus groups to examine ways of increasing access to the CIS, especially by underserved populations.
- Tailor efforts to reach a wider range of cultural groups.
- Examine ways of providing information that are independent of technological media.
- Develop new ways to assess and evaluate the audiences the CIS is reaching and the impact on special populations.

Office of Cancer Communications **(Susan Butler, team leader)**

The Office of Cancer Communications (OCC) has a public affairs focus rather than a public education one. The principal functions of OCC's three major components include the following:

- *Mass Media Branch:* Responds to more than 12,000 media calls annually. Generates media attention by issuing news releases and organizing news conferences. Offers media training and public relations advice.
- *Health Promotion Branch:* Makes information about treatment, screening, prevention, and rehabilitation available to patients, the public, and the medical community, with special attention to the needs of special populations. Responsible for breast and cervical cancer education programs, 5-A-Day program to promote increased fruit and vegetable consumption, and other programs. Operates public inquiries office.
- *Information Resources Branch:* Supports other OCC branches and NCI programs by providing graphics and print production services, special events coordination, exhibits management, and other services.

Ms. Anne Lubenow of the Health Promotion Branch gave a presentation on Consumer Health Profiles, which OCC uses to help identify and understand different audiences in need of cancer education and outreach. The profiles are developed using information from a database that combines health behavior information with geographic, demographic, and lifestyle data. At the request of the DCLG; these data are available to advocacy organizations as they have been to others who are interested in delivering health messages to defined audiences. CIS outreach program managers are trained to interpret Consumer Health Profiles data and can make presentations about the uses of the data. Advocacy organizations interested in making use of the database should first contact the CIS.

Identified strengths of OCC include:

- The media trust and use information from OCC.
- A high level of coordination exists between OCC and other NCI programs, divisions, and offices, as well as other Federal agencies, cancer centers, and industry.

- Materials for the public are based on consumer research findings.
- OCC staff and the DCLG are willing to work with other advocacy groups to refine messages and improve materials.

Weaknesses include a lack of routine assessment of how well messages are received at the time of delivery. For example: Mr. Paul Van Nevel, Associate Director for communications, said that OCC monitors media coverage of NCI news conferences, but does not routinely examine to what extent the public receives the information that is conveyed through the media.

OCC's promotion of information through exhibits is confined almost exclusively to meetings of the scientific community: However, consumer groups can also use these exhibits by contacting the CIS. Ms. Nelvis Castro, chief of the Health Promotion Branch, passed around a binder containing information about exhibits that can be adapted for consumer audiences.

Mr. Van Nevel said that OCC stopped producing TV and radio public service announcements several years ago because they were costly and generally did not receive good exposure. However, this policy is currently under review due to requests from cable outlets. Ms. Castro said that NCI print public service advertisements have appeared in consumer magazines such as *Good Housekeeping* and *Better Homes and Gardens* as well as advocacy group newsletters and medical journals. Mr. Van Nevel said that OCC uses outside public relations contractors for long-range media placement work, such as placing stories in women's magazines for National Breast Cancer Awareness Month, but that day-to-day media contacts are handled by NCI staff.

Recommendations for OCC include:

- Consider opportunities for the DCLG and other consumer advocates to assist in developing, refining, and communicating messages to the advocacy community and beyond.
- Do more to assess the effectiveness of the messages communicated by OCC (who is being reached, who is not being reached).
- Consider how messages communicated by OCC can be sustained in the media and in the public's mind.
- Do more to "put a face" on messages about cancer research.
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Ms. Castro and Mr. Van Nevel said that they would value guidance from the DCLG on how to better communicate cancer information to advocacy groups well as to non-English speaking groups. Ms. Castro said that her office is working with a Vietnamese American community organization in California that developed materials on cervical cancer to distribute these materials to other Vietnamese-speaking communities around the country. This is a model that could be extended to other non-English-speaking communities and other types of cancer.

Issues to be considered include what kinds of cancer information would be most useful, what resources community groups have that might be distributed more widely, and whether NCI needs a process for reviewing foreign-language materials produced by local organizations. Mr. Moore suggested that, as an interim measure, NCI make efforts to reach non-English-speaking individuals by reaching out to their English-speaking children, who can then translate the information for their parents.

Clinical Trials Promotion (Two Initiatives)

The NCI Office of Clinical Research Promotion is responsible for promoting extramural NCI-sponsored clinical trials that are conducted at cancer centers, through cooperative groups, and at institutions around the country. The Division of Clinical Sciences oversees intramural clinical trials conducted on the NIH campus in Bethesda. According to NCI statistics, each year 2-3% of eligible adult patients and 60% of eligible children enroll in treatment trials. Reasons why more patients do not participate in trials include:

- Many physicians do not refer patients to trials.
- Many physicians and patients are not well informed about trials or have negative perceptions of trials.
- Many managed-care health plans will not cover the patient care costs of treatment in clinical trials because of concerns that such treatment is more expensive than standard treatment.

NCI promotes participation in clinical trials by making sure that trials are funded, educating the public about trials, and promoting enrollment. NCI pays both research and patient care costs for trials conducted at the NIH hospital in Bethesda. NCI pays research costs, but not patient care costs, for NCI-sponsored trials conducted in the extramural community. NCI has agreements with the Department of Defense (DoD) and the Veteran's Administration (VA) under which those agencies' health plans will cover the patient care costs of employees and retirees who enroll in NCI-sponsored clinical trials. NCI is funding several studies to evaluate the cost of treatment in clinical trials compared with standard treatment.

NCI educates the public about clinical trials and promotes enrollment in several ways. Information about trials is available through the CIS and through NCI websites, including CancerNet® and cancerTrials®. A clinical trials training program is offered for physicians, nurses, and social workers and a Web-based program to educate physicians about trials is in development. A pilot program is under way to partner with local organizations to promote awareness of clinical trials in an urban population in Baltimore and a rural population in North Carolina. NCI is also stepping up its promotion of the clinical trials coverage benefit for DoD and VA health plan enrollees.

The cancerTrials website (http://cancertrials.nci.nih.gov), which has been in existence for about a year, offers general information about clinical trials and how to decide whether to participate in a trial, directories of trials and other NCI resources, news about cancer research, and a "contact us for information" link. Ms. Stewart emphasized that this website, developed by the Office of

Clinical Research Promotion, is a major step forward in NCI's efforts to promote clinical trials participation, and that the DCLG review team's comments were intended to make an excellent resource even better and more accessible.

Many feedback respondents found the information on the cancerTrials site to be current, comprehensive, and easy and fast to access. However, some noted that the site did not list all ongoing clinical trials and that it was difficult to sort trials by state. Ms. Stewart noted that individuals can subscribe to a cancerTrials listserv and receive regular updates by email.

The cancerTrials site was not easily found using several different Web search engines.

Suggestions for making the site easier to find include:

- Placing banner ads on search engines with links to CancerNet and cancerTrials.
- Working with search engines to put these sites on lists of recommended websites.
- Linking other NCI websites to cancerTrials.

The following points emerged in a discussion about how to help consumers more readily locate information about clinical trials and other NCI resources on the Web:

- A single point of entry to NCI's website would be less confusing for consumers.
- A standard format for all descriptions of clinical trials would be helpful.
- A method is needed to distinguish NCI-supported trials from other trials listed on the cancerTrials site.
- NCI is trying to develop a collaborative relationship with CenterWatch, a privately operated website that lists clinical trials, many of which are funded by pharmaceutical companies. Some NCI-funded investigators have independently chosen to list their trials on the CenterWatch site.
- It would be desirable to have a system whereby individuals could receive regular updates concerning trials that would meet their needs. NCI could not operate such a system, however, because it cannot retain identifying personal information about individuals. One possibility might be for a "trusted partner," such as an advocacy organization, to operate the system on NCI's behalf.

Using the cancerTrials website is easy unless the user wants to do a PDQ search, Ms. Stewart said. The following suggestions were made for improving the PDQ search form and user's guide:

- Allow users to narrow their search by specifying patient age, stage of disease, and diagnosis subtype. (Ms. Hubbard said that this is being done.)
- Consider whether the choices in the sponsorship field are useful for patients. Either reduce the number of choices or explain what the subgroups are in a hyperlinked user's guide.
- Organize the choices in the modality field more logically (e.g., alphabetically). Include commonly used terms to describe modalities.
- Place a "help me" box by each field on the search form, linking to an explanation of that field in the user's guide.
- Add an explanation of Phase IV clinical trials.
- Add a paragraph to make it clear that medical care is free for patients taking part in trials on the NIH campus in Bethesda.

Suggestions for improving the screen display of the results of a PDQ trial search included the following:

- List the trials in a logical order.
- Clearly indicate what kind of trial it is (Phase I, etc.).
- Add white space to make the patient list more readable.
- Include the title of the trial on both the patient and physician lists. If possible, add a brief description of the trial on the patient list.

Other suggestions for improving the cancerTrials website and strengthening other clinical

trials promotion efforts included the following:

- Ask or require NCI-supported cancer centers to list their trials.
- Ensure that all NIH cancer-related trials are listed.
- Provide criteria for listing non-NCI-supported trials.
- Require NCI-sponsored trials to use the revised informed consent document.
- Educate local librarians on how to help patrons access cancer information and serve as health centers for the underserved and those without internet access. (Ms. Hubbard said that a pilot program involving libraries in Maryland is under way.)
- Ensure that CIS information specialists give appropriate relative emphasis to both standard care and clinical trials and mention that trials on the NIH Bethesda campus are available at no charge.
- Increase efforts to train researchers to recruit from medically underserved populations.

Clinical trials taking place on the NIH campus are now listed on the BethesdaTrials page (www-.dcs.nci.nih.gov/trials) of the NCI Division of Clinical Sciences' (DCS) website. Information about these trials is also available by a toll free telephone number through the Clinical Studies Support Center (CSSC) (1-888-NCI-1937). Most patients in these trials are recruited from the greater Washington, D.C. area. Outreach efforts by DCS to promote the on-campus trials include meetings with local advocacy groups, partnerships with physician groups, and the use of teleconferencing and "telescreening" to reduce the travel burden for patients. Dr. Edison Liu, DCS director, noted that more than 200 intramural clinical trials are being conducted. Both the CSSC and the BethesdaTrials website, which has been in existence for less than a year, were established to streamline information about NCI's intramural clinical trials program for NCI staff and clinical investigators as well as for patients. Promoting the existence of NCI's intramural clinical trials program nationally was not a primary intent. However, the BethesdaTrials site will be linked to the redesigned PDQ.

The DCLG team expressed concerns that the BethesdaTrials website is very difficult to navigate and about whether the collaborations between the CIS, the OCRP, and the CSSC are as strong as they could be to help patients find cancer information.

Discussion

Patient-Doctor Communication

DCLG members observed that many of the respondents provided feedback said they used the information obtained from PDQ or CIS to help them to talk with their doctors. It was noted that this issue had been raised at previous DCLG meetings and that patient-doctor communication appeared to be a widespread problem. Several organizations, including the National Institute on Aging, the American College of Surgeons Commission on Cancer, the Office of Cancer Information, Communication and Education (OCICE), and the National Health Council (NHC) have produced publications for patients on the subject of talking with their doctors. Ms. Bowen agreed to send copies of the NHC publication to OCICE.

Mr. Katz said that there are two aspects to this issue: training physicians in how to better communicate with their patients and training patients in how to navigate the health care system to obtain the information and support they need without relying entirely on their doctors. Ms. Leigh said that the National Coalition for Cancer Survivorship (NCCS), in partnership with the Oncology Nursing Society and the Association of Oncology Social Workers, developed a

"patient toolbox" that teaches skills in communication, negotiation, decision-making, and self-advocacy.

Ms. Kathy Crosson, chief of NCI's Patient Education Branch, outlined the efforts being undertaken to promote The Cancer Journey, a training program for health professionals developed in partnership with NCCS and Ortho-Biotech, Inc. This program focuses on issues of cancer survivorship. Ms. Rogers said that Y-ME has developed a program entitled *In My Shoes: From a Patient's Perspective* that promotes more effective communication between health professionals and patients.

Appropriateness of Cancer Information Materials for Patients

Mr. Katz identified several dimensions of appropriateness: length and complexity (recognizing that some patients prefer information to be presented briefly and simply while others want greater depth and complexity) and cultural sensitivity and relevance, which includes availability in languages other than English. Ms. Hubbard distributed a handout that included information from the U.S. Census Bureau on languages spoken at home and ability to speak English in the U.S. population as well as information from NCI on the burden of cancer in various racial and ethnic groups. The DCLG expressed interest in helping NCI identify which languages should be of high priority in translating information.

PDQ Redesign

Ms. Hubbard said that usability testing of the PDQ redesign would be conducted at forthcoming meetings of the American College of Physicians, the Oncology Nursing Society, and the American Society of Clinical Oncology. She invited DCLG members to participate in the testing, at these meetings or by special arrangement with OCICE. She said that OCICE will pay the travel costs of DCLG members who wish to take part in special testing sessions. One-third of those involved in testing so far have never before used a computer, she said. Other groups taking part in the usability testing include underserved populations, health professionals, cancer patients, and families and friends of patients. Ms. Butler said that advocacy organizations could also provide access to their members as usability test participants.

Ms. Hubbard noted that one clear recommendation that emerged in planning sessions for the redesign, was that information should be labeled according to its level of technical detail and not according to assumptions about who the reader might be. Thus, identification of information as "for patients" or "for professionals" would be discontinued. Alternative terms such as "quick" and "advanced" are being tested with users. Ms. Hubbard said that the redesign planning group would like to rename PDQ, and she invited DCLG members to suggest new names.

Mr. Katz said that, in addition to DCLG participation in usability testing, he would like to see the DCLG represented on the committee that will make the decisions concerning the final configuration of the redesign.

Ms. Hubbard emphasized that OCICE is working in close collaboration with the Office of Clinical Trials Promotion. The cancerTrials website is part of the PDQ redesign and is being subjected to the same usability testing program.

Accessibility and Visibility of NCI Communications Programs on the World Wide Web

Although the DCLG's initial review did not include review of NCI's website, the feedback process identified a number of problems relating to the visibility of NCI programs and services on the Web. Multiple gateways to NCI information make it difficult for users to be sure they have obtained all of the information that is available and create the impression that NCI programs are uncoordinated and possibly duplicative. Ms. Hubbard noted that the redesign of NCI's website is another of her responsibilities and said that she would ensure that the DCLG's concerns are addressed.

Need for Consistent Presentation of Clinical Trials Information

Mr. Katz said that consistent presentation of clinical trials information on different websites would be extremely helpful to consumers. It would also permit consistent linkages to be established between sites. Another useful advance would be to enable consumers to readily identify all trials for their cancer type in a given state or region.

Promotion of Revised Informed Consent Template

It was noted that adoption of the revised informed consent template is occurring very slowly. Ms. McCabe, Director, Office of Clinical Research Promotion (OCRP) said that although the new template had been greeted with general enthusiasm, it was proving difficult to get Institutional Review Boards to change their procedures and actually use it. The OCRP will be holding a series of meetings to further promote the template and identify the barriers to its use.

Conclusions

By June 1, 1999 DCLG members will prepare a report with feedback and recommendations to Dr. Klausner. Ms. Nealon thanked the members for their hard work on the communications initiative. Mr. Katz said that one lesson learned from this process is that perceptions of NCI among those in the outside world are very different from the perceptions of those inside NCI. The challenge will be to make the public aware of the NCI resources and make them capable and friendly enough to have the desired impact, as well as to get the word out to those who don't use current communications vehicles (telephone and Internet). NCI must recognize that addressing consumer issues requires a focus on "touch points" and capabilities that span "functional silos" within the Institute.

Mr.Katz expressed the hope that this process would begin to bridge these perspectives. Another lesson is that many other entities use NCI resources and funding to develop a much higher profile with consumer audiences than NCI itself has. This raises the issue of whether NCI should attempt to take a leadership role in reaching consumers or should limit its role to providing resources, data, and funding to partners who interact with the public.

DCLG members said that engaging in this process had been enormously educational for them. The interaction with NCI staff and the opportunity to obtain direct feedback from consumers had been valuable. Dr. Hodge noted that many individuals who had submitted feedback had added their thanks for being given the opportunity to express their views. It was agreed that the ultimate value of this process would be demonstrated by the extent to which the issues identified by the DCLG as priorities lead to visible changes in NCI's communications initiatives. Mr. Katz said that he would like to see the DCLG engage in an ongoing effort to

obtain consumer feedback.

CONSUMER INVOLVEMENT IN PEER REVIEW

Dr. Marvin Kalt, director of NCI's Division of Extramural Activities (DEA), reported that within the past year, NCI expanded consumer involvement in peer review to include clinical cooperative groups, cancer centers, and program projects. One of the lessons learned is that consumers' participation in reviewing complex, multi-project applications involving site visits is very different from reviewing individual research proposals. Group orientation efforts for consumer reviewers have lagged, in part because of pressures on staff time. The proposal to produce an orientation videotape is on hold. The current thinking is that the best use of a videotape might be to present a mock peer review meeting or a mock site visit, introducing viewers to the conduct and dynamics of these events. Because NCI's structure, funding mechanisms, etc., are in a state of flux, information about these topics might be better presented in a Web-based format that can be updated more readily than a videotape.

About 40 individuals out of 150 whose names are on file have so far served as consumer reviewers; some have served on multiple review panels. Consumers are now participating in all reviews except those of basic science research proposals. Dr. Kalt said that he anticipated another 20 individuals would be asked to serve as consumer reviewers over the next year. Because the number of people currently available to serve as consumer reviewers is more than adequate to meet the expected need, solicitation of additional consumer reviewers will be done in conjunction with the DCLG to develop a process for recruiting consumer reviewers that piggybacks on the process by which the DCLG itself is selected. Previously the DCLG members established the criteria to be used to identify appropriate consumer advocates to serve.

Dr. Kalt invited DCLG members to comment on two documents that DEA had drafted to help consumer reviewers to better understand grant proposals: *The NCI Consumer Advocates' Cancer Glossary for Peer Review* and *The NCI Consumer Advocates' Guide to Peer Review of Cancer Centers, Clinical Cooperative Groups, and Program Projects*. Members suggested that addition of a pronunciation guide and a list of acronyms to the glossary would be helpful. Dr. Kalt said that a comprehensive list of acronyms is being compiled.

DCLG members said that what consumer reviewers would find most helpful is a simple, non-bureaucratic, practical guide to what they should expect and what they are supposed to do as participants in a peer review process. It was suggested that consumers rather than NCI staff should actually write the consumer advocates' guide to peer review or that DEA collaborate with OCC or the Patient Education Branch, both of which have experience presenting information to the general public.

Dr. Kalt said that efforts are being made to set up a mentoring system to link experienced and new consumer reviewers, at the DCLG's suggestion. He added that he would be willing to explore the feasibility of setting up mechanism such as a listserv that would enable individuals who have served as peer reviewers to network with each other.

MECHANISMS FOR ONGOING DIALOGUE WITH THE ADVOCACY COMMUNITY AND THE PUBLIC

Ms. Nealon explained that the DCLG's communications initiatives review could not include a

formal survey because there was not enough time to obtain clearance. Federal agencies must obtain clearance to conduct surveys from the Office of Management and Budget, a process that typically requires six months or more. OLA is exploring whether a chartered advisory committee such as the DCLG could receive a blanket clearance to collect feedback from consumers on an ongoing basis.

The group discussed whether the DCLG should develop a public identity and establish mechanisms to invite public comments and input. One suggestion was a website that incorporates an email response form. Ms. Lee said that OLA receives occasional calls from members of the public who want to provide input to the DCLG. Ms. Nealon said that OLA will develop a system for tracking correspondence addressed to the DCLG, and members will be asked to respond.

Issues the DCLG identified for future consideration include the following:

1. Review NCI activities aimed at improving patient-doctor communication. Possible strategies include:

- Communication training for doctors.
- Dissemination of materials produced by American College of Surgeons, National Health Council, National Institute on Aging, etc. to help patients talk with their doctor.
- Empowerment of patients to use the health care system to obtain the information they need.
- Linkages with consumer and professional organizations.

2. Review appropriateness of NCI materials in terms of depth, complexity, language, cultural relevance, duplication, consistency of messages, decision-making processes, etc.

3. Review NCI's efforts to improve the accessibility of its services and resources.

4. Participate actively in decision-making as well as usability testing of PDQ redesign.

5. Assist NCI in redesigning and better promoting its website.

6. Collaborate with NCI Office of Cancer Communications to refine communications messages and strategies.

7. Participate in further development of cancer communications Extraordinary Opportunity and associated RFAs.

8. Explore use of "trusted partners" to develop and disseminate tailored responses to individual requests for cancer treatment information.

9. Promote consistent presentation of clinical trials information on all websites (NCI, cancer centers, CenterWatch, etc.).

10. Promote use of revised informed consent template.

11. Explore ways of establishing ongoing contact among consumer participants in NCI peer

review.

12. Explore how the DCLG might work on the issue of the unequal disease burden and unequal health outcomes.

The priorities for consideration will be determined by the DCLG.

OTHER BUSINESS

Ms. Nealon said that DCLG members would shortly be receiving copies of the "genetics primer", Understanding Genetic Research and Population-Based Studies along with a form for comments on the primer's usefulness.

ADJOURNMENT

Mr. Katz thanked OLA for its work in support of the DCLG's activities. He also acknowledged the members of the OLA Advocates Committee who attended at the meeting. There being no further business, the meeting was adjourned at 3:05 p.m. on Tuesday, April 20, 1999.