

National Cancer Advisory Board (NCAB)  
*Ad hoc* Subcommittee on Communications

Hyatt Regency Bethesda Hotel  
Old Georgetown Room  
1 Bethesda Metro Center  
Bethesda, MD  
February 7, 2013  
6:30 p.m. – 8:30 p.m. EST

SUMMARY

Subcommittee Members:

Dr. Victoria Champion, Chair  
Dr. Maria R. Cruz-Correa  
Dr. Kevin J. Cullen  
Ms. Mary Vaughan Lester  
Dr. Jonathan M. Samet  
Dr. Lenora Johnson, NCI, Executive Secretary

NCAB Members:

Dr. Elizabeth Jaffee  
Dr. Beth Karlan

Other Participants:

Mary Anne Bright, NCI	Nina Goodman, NCI
Ben Carollo, NCI	Li Gwatkin, NCI
Nelvis Castro, NCI	Shannon P. Hatch, NCI
Julie Cheh, NCI	Brad Hesse, NCI
Jonathan Cho, NCI	Christie Kaefer, NCI
Robert Croyle, NCI	Barry Kramer, NCI
John Czajowski, NCI	Madeline La Porta, NCI
Kevin Davis, NCI	Richard Manrow, NCI
Allison Eckhardt, NCI	Kelli Marciel, NCI
Susan Erickson, NCI	Sona Thakker, NCI
Richard Folkers, NCI	Jennifer Lee, Rapporteur, The Scientific Consulting Group, Inc.
Paul Goldberg, The Cancer Letter	

**Introductions/Review and Overview**

Dr. Victoria Champion, Subcommittee Chair, opened the meeting at 6:40 p.m. She noted that the Subcommittee would be unable to achieve the outcomes outlined in the agenda because Dr. Harold Varmus first must appoint a Working Group from among the Subcommittee members that would be charged to advise the NCI on communications. Instead, Dr. Champion indicated that Dr. Lenora

Johnson would present an overview of the structure and budget of NCI's Office of Communications and Education (OCE) for discussion, and the meeting could adjourn earlier than scheduled.

Dr. Johnson drew Subcommittee members' attention to the minutes from the November 28, 2012, meeting and asked for comments or corrections. Ms. Mary Vaughan Lester stated that in the body of the minutes, she was referred to mistakenly as "Dr. Lester" rather than "Ms. Lester." Dr. Johnson noted the change.

Attendees present at the start of the meeting introduced themselves, and Dr. Johnson later introduced Ms. Susan Erickson, Mr. Rick Borchelt, and Ms. Kelli Marciel all who direct other OD offices with communication responsibilities for specific audiences; Congress, media, and advocates respectively.

### **NCI Office of Communications and Education: Structure and Budget Overview**

In her overview of the NCI OCE's structure and budget, Dr. Johnson focused on its mission, vision, and mandates as they have informed its structure; the Office's budget history; the core of the OCE's current communications enterprise; and the role that the Working Group might have in examining and making recommendations for the program, which she anticipated would emerge through the working group's discussions. Dr. Johnson described OCE's mission to disseminate evidence-based cancer information to the public, and the Office's vision to be valued as a trusted resource for information for the public. The NCI received a mandate to communicate, educate, and disseminate information to the public under the National Cancer Act of 1971.

Prior to 1997, the organizational structure of NCI's communications enterprise was relatively stable. From 1997 to 2007, there were numerous changes to the enterprise's structure as offices were split, merged, and integrated repeatedly; many of these organizational changes could have benefited from a more thoughtful approach. During this period, communication leadership was not always consistent. Among the most significant recent changes is the ending of the Cancer Information Service (CIS) Partnership Program and the consolidation to a single CIS contact center.

Housed within the NCI Office of the Director (OD), the OCE currently is comprised of five primary offices, three branch offices, and two Office of Cancer Content Management branches. Their respective oversight includes the following:

- *Primary Offices:* Cancer Content Management (OCCM), Communications Services (OCS), Partnerships and Dissemination Initiatives (OPDI), Market Research and Evaluation (MORE), and Public Information and Resource Management (OPIRM).
- *Branch Offices:* Communications, Planning and Coordination, Business Operations, and Communications Technology
- *Office of Cancer Content Management Branches:* Cancer Publications, and International Cancer Research Databank.

Subsequent to the retirement of the Associate Director of the OCS, it is planned that OCS will be integrated with the Business Operations Branch.

The OCE's total budget allocation declined by approximately \$23 M from fiscal year (FY) 2006 to FY 2012. During that period, the personnel budget was held constant. Currently, the OCE has 79 full-

time employees, but there have been no new hires in recent years, and this number is expected to continue decline through retirement and attrition.

The OCE has a highly reputable content base and a rich digital platform. As the use of social media has grown, the NCI has changed the way that it communicates with users, from a simplex platform to one in which social media allow the NCI to disseminate information to and receive information from users through the Institute's digital communication enterprise. Mobile technology has led to significant changes in NCI's communication program as well and will continue to cause the program to evolve. Currently, approximately one-half of OCE's operations budget is devoted to NCI's communications core, comprised principally of the digital media infrastructure, PDQ<sup>®</sup> (Physician Data Query) database, and the CIS Call Center. The goals of NCI's digital platforms are to disseminate information about cancer research progress; inform patients, family members, and caregivers; and enhance the public's trust of the science that the NCI supports.

### *Discussion*

Ms. Lester and Dr. Kevin Cullen sought further details from the NCI about the decline in the OCE's budget from FY 2006 to FY 2012. Ms. Lester asked whether the decrease was because of changing technology or greater efficiency. Dr. Cullen queried about the activities that the Office was no longer supporting but had supported in FY 2006. Dr. Johnson explained that, as the OCE's funding allocation declined, the Office adjusted by becoming more efficient, including consolidating contracts that were duplicative because they were legacies from previous organizational structures. In addition, the CIS Partnership Program ended in 2010 and the call center consolidated from 3 call centers to one single call center. In addition, some programs shifted to other parts of NCI for more appropriate alignment – the enterprise vocabulary system (EVS) to caBIG and the clinical trials registration to the clinical trials reporting program (CTRP) in CCCT.

Ms. Lester asked about the cause of the instability and lack of leadership in NCI's communication program prior to 1997. Dr. Robert Croyle replied that much of the instability in the organizational structure of NCI's communication program was attributable to the varying priorities of successive NCI's Directors. Dr. Champion expressed her opinion that it would be beneficial to stabilize the communication program's priority and focus. Dr. Cullen asked whether there was a formal strategic planning process for the program. Dr. Johnson replied that program undertook formal planning every 2 years, the last process rendered a set of communication objectives and tactics for 2010-2012, and she would share these with the Subcommittee.

Ms. Lester asked whether the NCI's expenditures on digital media likely would increase from current levels. Dr. Johnson answered that the NCI's communication technology infrastructure will migrate to the Center for Biomedical Informatics and Information Technology (CBIIT), and after an initial investment to upgrade at least one rather vulnerable platform, spending levels should not rise, particularly as technology has tended to become less expensive over time.

Dr. Jonathan Samet inquired about coordination of communication among the National Institutes of Health (NIH) Institutes and Centers (ICs), particularly to share research results, and whether NIH's OD supported such coordination. Dr. Johnson responded that coordination is increasing, and core Communication Directors from NIH institutes meet regularly and are encouraged by NIH's OD to collaborate (e.g., collaborating on exhibits at large conferences, consolidating warehouses).

Mr. Borchelt added that the NCI had taken a leadership role in communication among NIH's Institutes and Centers and that Dr. Johnson has been key in NIH's innovations in this area.

Dr. Cullen asked about metrics used by the NCI to evaluate its digital communication activities, including comparing its impact to that of other organizations, such as the American Cancer Society (ACS). Dr. Johnson replied that cancer.gov<sup>1</sup> Web page "analytics" are recorded routinely on a monthly and quarterly basis, including to evaluate the effects of a particular event or posting on website activity; the website of ACS is often accessed more frequently than that of the NCI. Dr. Champion asked about the tools that the NCI uses to determine the usability of its website. Mr. Jonathan Cho and Dr. Manrow answered that the NCI uses techniques such as eye-tracking (for cancer.gov), usability-testing, and focus groups (for cancer.gov en español<sup>2</sup>) and applies user-center research results to its web pages.

The Subcommittee asked about the role of social media in NCI's communication. Dr. Cullen inquired about measuring the effectiveness of using social media. Dr. Johnson stated that the NCI uses social media to insert NCI's content into "conversations" on such networks as Twitter and Facebook, and that this effort has been particularly valuable for reaching international and mobile audiences. Ms. Lester asked for clarification about the mechanism by which the NCI added content. Dr. Johnson answered that generally the NCI directs conversation participants to the relevant information on cancer.gov via a shortened hyperlink (tiny URL or bitly).

The continued use of print media was raised by Subcommittee members. Ms. Lester acknowledged that older generations might prefer receiving information in hard copy format but noted that a significant portion of the U.S. population accesses the Internet via mobile devices rather than computers. Dr. Johnson and Dr. Richard Manrow explained that printing represents a significantly smaller portion of NCI's communication budget than in the past, although print publications still are stored and orders continue to be filled at NCI's warehouse, including bulk orders by Cancer Centers and other organizations. Dr. Johnson added that packaging information for mobile devices is a new challenge for the NCI. Dr. Champion predicted that in the future, new technologies will become less expensive and therefore more widely adopted, and the NCI's information efforts will need to adapt to these changes.

The Subcommittee discussed the problem that, because NCI's communication products are in the public domain, third parties have produced their own print copies of the products and offered them for sale. Dr. Champion and Dr. Beth Karlan pointed out the need to educate the public about free versions available from the NCI. Ms. Lester suggested that the NCI collaborate with Mr. Jeffrey Bezos, chief executive officer (CEO) of Amazon.com, to disseminate NCI's printed products. Dr. Karlan suggested that a portion of third-party sales of NCI's materials be donated to the Institute. Dr. Manrow explained that the NCI, like all governmental agencies, is barred from expending funds on promotional activities; Mr. Cho cited the statistic that cancer.gov Web pages receive between 2.5 and 3 million unique visitors each month. Dr. Manrow noted that the Institute is investigating approaches to prioritize cancer.gov Web pages among Google search results. Dr. Karlan speculated that the public might give less credence to information that was available free of charge, but a governmental agency might be perceived as more reliable than a commercial entity as an information source. Dr. Johnson responded that data exist to support both perspectives.

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<sup>1</sup> Available from: <http://www.cancer.gov>.

<sup>2</sup> Available from: <http://www.cancer.gov/espanol>.

Ms. Lester proposed that the NCI consider a broad publicity campaign to bring attention to its information resources; the campaign might be considered an educational rather than a promotional activity. Dr. Karlan agreed with Ms. Lester’s suggestion, drawing attention to the Centers for Disease Control and Prevention’s (CDC) campaign to raise awareness about gynecological cancers. Dr. Croyle suggested that it would be valuable for the Subcommittee to suggest priorities for NCI’s communication program such as publicity campaign as well as topics for it (e.g., cancer screening, human papillomavirus [HPV] vaccination).

Dr. Karlan suggested that it would be valuable for the NCI to compile demographic information about those who access the Institute’s website, particularly whether most users were patients. Mr. Cho and Dr. Manrow replied that in one study—the results of which largely were confirmed by customer satisfaction survey responses—approximately 17 percent were international users, and of all users, 70 percent were patients or personally related to a patient, 20-25 percent were healthcare professionals, and the balance were “other.”

Dr. Champion suggested that, after Dr. Varmus appoints a Working Group from the *Ad Hoc* Subcommittee on Communications, the Working Group likely will consider communication collaboration opportunities with the ACS. She anticipated that once formed, the Working Group would meet by video, teleconference, and/or face-to-face at least twice before the June 2013 NCAB meeting.

Dr. Champion thanked attendees and adjourned the Subcommittee meeting at 7:50 p.m. EST.

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Dr. Victoria Champion  
Chair

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Date

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Dr. Lenora Johnson  
Executive Secretary

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Date