

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

**Hyatt Regency Bethesda Hotel
Judiciary Room
1 Bethesda Metro Center
Bethesda, MD
June 23, 2013
6:45 p.m. – 8:15 p.m. EDT**

SUMMARY

Subcommittee Members Present:

**Dr. Victoria Champion, Chair
Dr. Kevin J. Cullen
Dr. Beth Karlan
Dr. Jonathan M. Samet
Dr. Lenora Johnson, NCI, Executive Secretary**

Board of Scientific Advisors (BSA) Members:

**Francis Ali-Osman, BSA
Mary Lou Smith, BSA**

National Cancer Advisory Board (NCAB) Member:

Dr. Marcia Cruz-Correa

Other Participants:

**Nelvis Castro, NCI
Robert Croyle, NCI
Bethany Drehman, Federation of American
Societies for Experimental Biology
Susan Erickson, NCI
Kay Fleming, NCI
Richard Folkers, NCI**

**Paul Goldberg, The Cancer Letter
Jennifer Hobin, American Association for
Cancer Research
George Komatsoulis, NCI
Barry Kramer, NCI
Jennifer Lee, Rapporteur, The Scientific
Consulting Group, Inc.**

Introduction

Dr. Victoria Champion, Subcommittee Chair, opened the meeting at 6:45 p.m. Dr. Champion reported that since the Subcommittee's previous meeting on February, 7, 2013, meeting, many events had occurred. Budget imperatives had required immediate actions to reduce expenditures by the Office of Communications and Education (OCE). Dr. Champion stated that this meeting would provide an opportunity for a full update.

Dr. Champion asked the members of the Subcommittee to introduce themselves. She indicated that all members were in attendance with the exception of Mr. William Goodwin. Later in the meeting, the other attendees introduced themselves.

Dr. Champion reviewed the highlights of the previous meeting in February. When the Subcommittee met, they understood that they had been given a charge by the NCI. At the meeting, however, they learned that to have a charge, they needed to be appointed as a working group by Dr. Harold Varmus, Director, NCI. For various reasons, did not occur.

As the first order of business for the meeting, Dr. Champion asked the Subcommittee members whether they had reviewed the minutes from the February 7, 2013, meeting and if so, whether there were any comments on or corrections to the minutes. She noted that the minutes were not included in the meeting materials received by the Subcommittee members, but they were distributed via email prior to this meeting to the members.

Motion: The minutes of the February 7, 2013, Subcommittee meeting were approved unanimously.

Dr. Champion noted that at the February meeting, the Subcommittee had requested three items of information from the NCI. These items were: (1) the strategic objectives for the OCE; (2) an analytic report on key metrics for NCI's digital platforms; (3) and a comparison of Cancer.gov metrics to other organizations. Also included in the meeting materials was a new charge for the Subcommittee. This charge, provided by Dr. Varmus and Mr. John Czajowski, Deputy Director for Management and Executive Officer, NCI, was intended to best use the efforts of the Subcommittee. It focuses on the Web presence of the NCI.

Dr. Champion reviewed the agenda. One of the agenda items was for the Subcommittee to examine the new charge, which is more circumscribed than the original charge but still broad in scope.

Update From the February 2013 Subcommittee Meeting

Dr. Lenora Johnson, NCI, Subcommittee Executive Secretary, described the analytic report, which provides a direct response about the requests for the data provided on Cancer.gov. The OCE produces these reports in an ongoing effort. Dr. Johnson drew the Subcommittee members' attention to the benchmarking data on page 4 of the report, which compared the NCI's website with those of eight comparable websites from other organizations.

One unusual event in the data was a response to the actor Angelina Jolie's decision to undergo a double mastectomy in response to genetic testing that indicated a *BRCA1* mutation conferring elevated risk of breast cancer. Public interest in Cancer.gov, NCI's social media outlets and its toll-free information number of web hits increased dramatically. The public sought information about preventive mastectomy and *BRCA1*. This provided evidence that when lay people engage in conversations about cancer, they consult Cancer.gov as an informational resource. Dr. Beth Karlan asked whether there had been a similar response to Michael Douglas' announcement that linking his oral cancer to human papilloma virus (HPV) infection. Dr. Johnson responded that she has not examined the statistics about that announcement.

Dr. Johnson also noted that Dr. Varmus uses the NCI website to communicate with the research community. He has had six or seven posting since he started as NCI Director. Some postings are addresses to national conferences; some are messages to the research community. The latter category includes a message dated March 7, 2013, which describes sequestration's impact upon the NCI budget and its effects on NCI's research portfolio. On May 7, 2013, Dr. Varmus issued a message on

appropriations, describing the impact of a shortfall in the budget on the NCI and how it would be handled to protect research.

Dr. Johnson described Congressional activities related to communication. A letter dated April 12, 2013, from an Energy and Commerce Communications Subcommittee members to NIH Director Dr. Francis Collins was a response to information on NIH's communications budget from articles in *The Cancer Letter* and *Nature*. On May 20, 2013, Dr. Varmus briefed a member and staff of the House Appropriations Committee and the chief counsel for oversight and investigation at House Energy and Commerce Committee (Bartrum and Slobodin respectively), about the NCI's communications budget and responded to questions. Dr. Johnson accompanied Dr. Varmus for this briefing as did Ms. Erickson.

Dr. Johnson noted the major changes that had taken place in the OCE's budget. There had been a 15 percent reduction in fiscal year (FY) 2013, and an additional budget reduction of 15 percent was expected in FY 2014. Staff members have been reassigned to other areas in the NCI. At the previous Subcommittee meeting, the participants had talked about the large fraction of OCE's budget that was devoted to personnel. The results of budget decisions have been a shifting of personnel. In addition, some projects have been discontinued. In response to a question by Dr. Cruz-Correa, Dr. Johnson provided more detail about some projects that had been transferred to other departments and others that had been stopped. Dr. Karlan proposed that strategic planning by the Subcommittee might highlight the added value of OCE's efforts. She suggested that the Subcommittee consider approaches to identify communications strategies that were compatible with a leaner budget.

Overview of Charge

Dr. Champion noted that the new charge was distributed via email to the Subcommittee members with the agenda. The Subcommittee was charged with examining the NCI's website. Specifically, problems exist that include costs associated with the production and magnitude of website activities, the lack of a cohesive NCI identity, the difficulty in ensuring standards, the lack of interconnectivity and the varied audiences.

The new charge includes examination of NCI's public facing web presence in operations and the levels of coordination in communication and content/data dissemination. A report will be issued discussing how NCI's web presence aligns with industry best practices and how efforts might be better coordinated, resourced, managed and made more efficient. She noted that the audiences for the website were quite varied, including Congress, professionals, and the lay public. The specific charge of the Subcommittee is provided in the third paragraph, which Dr. Champion read to the attendees. Dr. Varmus asked the Subcommittee to evaluate how the Web presence compares with industry best practices as well as how the NCI's efforts might be made more efficient. In addition, the Subcommittee was asked to consider how the content and data on the NCI's website might be leveraged for use by other organizations. Dr. Champion reminded the participants that Dr. Kevin Cullen had raised the issue of overlap between the website of the NCI and the American Cancer Society (ACS) at the Subcommittee's first meeting. Relative to the scope of this charge, Dr. Champion noted that the NCI is second only to National Aeronautics and Space Administration (NASA) among government agencies in the number of pages on its website.

The Subcommittee members expressed concern that evaluating industry best practices in Web design was beyond their expertise. Dr. Jonathan Samat asked whether support from consultants would be

available to the Subcommittee. Dr. Karlan commented that the ACS website is excellent. She suggested that the NCI partner with the ACS. Dr. Champion observed that the ACS website received more than twice the number of visitors during the same period as the NCI, but Dr. Cullen pointed out that the ACS was promoting its 100th anniversary which might account for the growth in traffic to its site since March of this year. Dr. Champion also noted that not all of the material on the ACS site was written for a lay audience.

Descriptions of NCI's Current Website Configurations

Dr. George Komatsoulis presented an update on the technology and governance of NCI's Web presence. He noted the difference between websites and Web applications. Both are accessed by Web browsers, but they have different capabilities: websites are static whereas Web applications are transactional (i.e., data come in and go out). Web applications generally have specialized analytical capabilities and more complex technology. The governance by federal statutes differs as well.

Dr. Komatsoulis outlined a proposal to revise the underlying technology and governance of the NCI's web presence. He noted that NCI's approach had been federated website development. This approach allows websites to be built and deployed rapidly. Disadvantages include lack of a consistent look and feel, problematic integration, and difficulties with interconnectivity.

He presented a new governance map. The NCI's websites would be governed yet remain federated development content. To achieve this, a NCI website council would be established to: define common technology standards (i.e., lower cost); establish content standards (i.e., look and feel); and an approval process for new websites. There would be providers: infrastructure providers (internal like the Center for Biomedical Informatics and Information Technology [CBIT] outside providers, if more cost effective) and Web development providers. These providers would ensure that standards are upheld across all NCI websites.

Discussion and Next Steps

The Subcommittee discussed Dr. Kamatsoulis' presentation. Dr. Champion asked whether the NCI had centralized governance to approve Web applications or websites. Dr. Johnson replied in the negative. She indicated that there had been a process by which all ".gov" websites had to be approved by the Department of Health and Human Services (HHS). She added that the need for centralized approval of processes was an area on which the Subcommittee might offer advice to the NCI. Dr. Champion noted that Dr. Kamatsoulis' presentation addressed the process by which all content was developed for technology use but first the focus of content needed to be addressed.

There is duplication among websites that provide information on cancer. Dr. Cullen suggested that governance needs to involve other key providers. Dr. Jonathan Samet cited the very large number of websites that communicate about cancer. He stated that it would help to see how the NCI fits among other organizations that offer information. Dr. Barnett Kramer, Director, Division of Cancer Prevention (DCP), NCI, noted that it might not be sufficient to identify each organization and see at whom it is directing its energy. Each organization might have different process to develop information, even if they target the same audience.

The Subcommittee explored issues in the development of a consistent look and feel for the NCI website. Dr. Komatsoulis suggested that a NCI Website Council focused on establishing standards would ensure consistency across the NCI's Web presence. Dr. Samet noted that universities have tried to do this but seems to not have been helpful to impose uniformity, although reviewing for consistency has had positive results. It is possible for standards on consistency to become a barrier to communication.

Determining the audience for the NCI's website was expressed by Dr. Cullen to be a more fundamental question. He noted that both the NCI and the ACS built their websites from the ground up, trying to serve every audience. He proposed that the NCI core focus be on serving the research community by providing information on grant opportunities, sharing data, and informatics. He was less certain that the NCI should invest significant effort in providing information to the lay public. Dr. Karlan suggested the need to prioritize constituencies.

Dr. Johnson reminded the participants that the NCI has a federal mandate to communicate to the public. She added that much of what the NCI does in regard to patient/public outreach is in response to its legislative mandates. Dr. Karlan asked whether providing a hyperlink to information housed elsewhere might fulfill this mandate. This would be a way of leveraging limited funds to achieve a larger mission. Dr. Johnson stated that such depends upon how the Institute interprets the legislation. Dr. Susan Erickson offered to send the mandate via email to all Subcommittee members this evening. Dr. Kramer stated that it would be important for the Subcommittee to know its mandate. It also would be important to see whether prioritization of audiences exists within mandate.

Dr. Cullen proposed classifying websites by the type of information (i.e., "bucket") offered. In his practice, he uses three websites: Cancer.gov (research issues, treatment overviews); the ACS for cancer statistics as well as for patient information; and the National Comprehensive Cancer Network (NCCN) guidelines (evidence-based guidelines for treatment). Dr. Champion noted that the NCI provides information for all these categories.

The Subcommittee discussed logistics. Dr. Champion noted that the group needs information about the timeframe for its actions and available resources, and she would raise this with the Board and Dr. Varmus the next day. The group agreed to meet via videoconference(s) before the next in-person meeting. The videoconferences would allow the group to plan before September meeting.

The Subcommittee is included on tomorrow's agenda. It will be an opportunity to obtain feedback from Board members and to clarify the timeframe with Dr. Varmus.

Dr. Champion thanked attendees and adjourned the Subcommittee meeting at 8:04 p.m. EDT.

Dr. Victoria Champion
Chair

Date

Dr. Lenora Johnson
Executive Secretary

Date