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

Hyatt Regency Bethesda Hotel
Old Georgetown Room
1 Bethesda Metro Center
Bethesda, MD
November 28, 2012
7:00 p.m. – 8:00 p.m. EST

SUMMARY

Subcommittee Members:

Dr. Victoria Champion, Chair

Dr. Kevin Cullen

Dr. Judith Kaur

Ms. Mary Lester

Dr. Jonathan Samet

Dr. Lenora Johnson, Executive Secretary

NCAB Members:

Dr. Bruce Chabner

Dr. Tyler Jacks

Dr. Olufunmilayo Olopade

Other Participants:

Mr. Rick Borchelt

Dr. Wen-ying (Sylvia) Chou

Dr. Robert Croyle

Mr. Paul Goldberg

Ms. Kelli Marciel

Ms. Cassie Norman

Dr. Abdul Shaikh

Dr. Jennifer Lee, Rapporteur

Welcome and Opening Remarks

Dr. Victoria Champion, Subcommittee Chair, welcomed meeting participants. NCAB members and other participants introduced themselves.

Dr. Champion read the Subcommittee's charge: "This ad hoc subcommittee provides advice on issues relating to cancer information and the communication of that information to the constituencies of the NCI including the public, patients, physicians and health care professionals, researchers, advocacy and professional organizations, the media and Congress. It will also provide input to NCI's Office of Communications and other organizational units within the NCI that are engaged in activities which are relevant to cancer communications."

The Subcommittee last met in 2008, when it offered advice to the NCI on its planned reorganization of the infrastructure of its communications activities. Dr. Champion said that she viewed the current meeting as an organizational one, providing the Subcommittee with the opportunity to clarify how it could assist the NCI most effectively. She added that health communications will be the focus of the President's Cancer Panel in 2013–2014.

Discussions and New Business

Communication activities undertaken by the NCI are multifaceted, and Dr. Bruce Chabner asked for clarification about their nature from NCI staff. Within the Division of Cancer Control and Prevention (DCCPS), directed by Dr. Robert Croyle, the Health Communication and Informatics Research Branch (HCIRB), housed within the Behavioral Research Program, administers NCI's extramural research program on the effects of health communication of cancer-related outcomes. Dr. Lenora Johnson directs the Office of Communications and Education (OCE), which has as its mission the dissemination of research results to the public. The Office of Public Affairs and Research Communication, also under the Office of the Director, provides outreach to the news media and policy makers about advances in cancer research that were supported by the NIH. Mr. Rick Borchelt serves as Special Assistant for Public Affairs in the Office of the Director.

Dr. Croyle provided context for the initiatives of the HCIRB. Under bypass budget planning, the NCI had established cancer communications as one of its priorities. Among the initiatives funded were the launch of NCI's website and the Centers of Excellence in Cancer Communication Research (CECCR). Funding for many of these initiatives is expiring and is not expected to be renewed. Dr. Croyle commented that although the HCIRB is at the center of NCI's communications effectiveness research program, communication is a key part of many of NCI's other programmatic activities, such as research on outcomes, policy, and global health.

Dr. Tyler Jacks recognized the broad scope of the Subcommittee's charge and pressed NCI staff for more details on the issues facing the NCI that are related to communications. He asked what had prompted the NCI to ask the Subcommittee to reconvene. Dr. Johnson replied while she did not know what prompted the reconvening of the Subcommittee, Dr. Varmus has expressed concern about the amount of resources invested by the NCI in communications activities during the current period of fiscal restraint. She felt the Subcommittee could provide advice on how the NCI should invest its resources in communications most appropriately. Mr. Borchelt stated that he and Dr. Johnson were asked by Dr. Varmus to compare models of the communications efforts of different Institutes within the NIH and found a high degree of variability in spending levels and approaches, including the formation of external partnerships.

Dr. Champion summarized that there are two components of NCI's communication activities: outfacing and effectiveness research. Dr. Croyle specified that the role of the Board of Scientific Advisors (BSA) is to advise the NCI about research priorities, including research on health communication effectiveness. Dr. Champion responded that therefore, it was her understanding that the NCI intended the Subcommittee to focus on the first component. Dr. Abdul Shaikh suggested he and Dr. Wen-ying (Sylvia) Chou not present the material that they had prepared for the Subcommittee, as it pertained chiefly to the second component of NCI's communications efforts. Dr. Champion expressed her

opinion that the Subcommittee needs to educated further about the nature of NCI's out-facing communication efforts.

Mr. Borchelt indicated that the NCI sought the Subcommittee's input as to whether those communications efforts by the Office of the Director are aligned with best practices. He stated that they currently are performed by four independent offices, of which the OCE is the largest. The other three are the offices of Government and Congressional Relations, Public Affairs and Research Communication, and Advocacy Relations. Dr. Johnson noted that her office's budget, although it was currently \$42 million, has been reduced by about 40 percent since the previous Subcommittee meeting.

Dr. Kevin Cullen described investigations of possible collaboration of health education efforts between the American Cancer Society (ACS) and the NCI to which he had been a party, as had Dr. Johnson. He expressed the opinion that there was significant redundancy in efforts, and both organizations would benefit from collaboration given the current fiscal climate. Dr. Johnson replied that mechanisms were needed for consolidation, and challenges exist although the institutions are willing. For example, differences in distribution policies (ACS sells materials whereas the NCI does not) and vetting requirements, which are more stringent for the NCI, can cause tension. Dr. Mary Lester inquired as to the extent of overlap between the communications activities of the ACS and NCI, to which Dr. Johnson replied that it was significant. Dr. Champion asked Dr. Cullen to provide an overview of ACS's communication efforts at the next Subcommittee meeting. Mr. Borchelt stated that the Centers for Disease Control and Prevention (CDC) has assumed responsibility for all of the health communications of the National Institute of Allergy and Infectious Diseases (NIAID). Tension can result from these collaborations, however, because of potential conflicts of interest, such as advocacy groups using NCI's messages to further their fundraising goals. Mr. Borchelt proposed that the Subcommittee could provide the NCI with guidance on the appropriateness of collaborating with external parties to produce information.

Regarding other methods of economizing on communication outreach, Dr. Olufunmilayo Olopade asked whether OCE has discontinued producing printed material. Dr. Johnson answered that her office is working to eliminate bulk distribution of products but still provides individualized outreach materials, either by postal or electronic mail. Dr. Chabner expressed concern that those who need information the most might not have access to the Internet. Dr. Johnson responded that the disenfranchised tend to rely heavily on mobile devices, and her office is exploiting the use of mobile tools and platforms. Dr. Chou noted that much of HCIRB's research focuses on identifying the audience that receives health communication messages, and there has been intense interest on the topic in the research community. She volunteered to present current data and research on the effects of new forms of communication on cancer-related outcomes to the Subcommittee. Dr. Champion agreed that this would be valuable to the Subcommittee and could be presented at its June 2013 meeting.

Dr. Shaikh described a meeting in August 2012 among the NCI, CDC, ACS, and other partners on the state-of-the-science in communications for cancer. Both research and practical applications were discussed. A white paper was generated from the meeting. He offered to share the results of the meeting with the Subcommittee.

Dr. Champion asked participants whether they had additional issues that they wished to raise. She indicated that the evening's discussions had produced a full agenda for the next Subcommittee meeting.

Future Meetings

The following were suggested as agenda topics for future meetings:

• Overview of the activities of NCI's Office of Communications and Education—Dr. Johnson

Date

- Summary of ACS's communication activities—Dr. Cullen
- State-of-the-science in communications for cancer—Dr. Shaikh
- Effects of the changing communications landscape on health—Dr. Chou

The Subcommittee meeting adjourned at 7:53 p.m. EST.

Dr. Victoria Champion Date Dr. Lenora Johnson Chair Executive Secretary