

National Cancer Advisory Board (NCAB)
Ad hoc Subcommittee on Global Cancer Research (GCR)

Hyatt Regency Bethesda Hotel
Embassy/Patuxent Room
1 Bethesda Metro Center
Bethesda, MD
February 27, 2012
6:40 p.m. – 8:30 p.m. EST

SUMMARY

Subcommittee Members:

Dr. Olufunmilayo Olopade, Chair
Dr. Kevin Cullen
Dr. Marcia Cruz-Correa
Dr. Kim Lyerly
Dr. Karen Meneses
Dr. Edward Trimble, Executive Secretary

NCAB Members:

Dr. Victoria Champion
Dr. Judith Kaur
Dr. Waun Hong

Other Participants:

Parag Aggarwal	Douglas Lowy
Teri Brown	Damali Martin
Nelvis Castro	Cathy Muha
Henry Ciolino	Ben Prickril
Geraldina Dominguez	Karl Poonai
Kalina Duncan	Michele Powers
Brenda Edwards	Julie Schneider
Mark Fleury	Sudha Sivaram
Silvina Fredi (sp?)	Lisa Stevens
Jorge Gomez	Juan Tayco
Todd Hardin	Emmanuel Taylor
Joe Harford	Makeda Williams
Libin Jia	Debbie Winn
Lenora Johnson	Erinn Howard, Rapporteur

Welcome and Opening Remarks

Dr. Olufunmilayo Olopade, Subcommittee Chair, welcomed meeting participants. NCAB members introduced themselves.

Cancer Research in the Media: An Inter-American Workshop for Scientific Journalism

Nelvis Castro

Dr. Edward Trimble, Director, the National Cancer Institute (NCI) Center for Global Health (CGH), introduced Ms. Nelvis Castro, who informed participants about a scientific journalism workshop.

Ms. Castro explained that the Inter-American Workshop for Scientific Journalism has the dual purpose of enhancing journalist skills in communicating cancer to the public, as well as increasing awareness among Hispanic/Latino journalists about cancer research and its impact on public health. The workshop took place in Guadalajara, Mexico, and there were eight countries represented in attendance.

The unique feature of this workshop, as compared to previous workshops, was that scientific talks were paired with journalist topics, such as cancer research and burden in Latin America, covering cancer news, and evaluating health stories, among others. Ms. Castro said that social media was utilized at the workshop. For example, there were 300 live Twitter “tweets” created during the workshop.

The workshop currently is undergoing evaluation to determine if the participating journalists are applying what they learned to their daily work and if the quality of cancer coverage among participants has altered or improved.

Ms. Castro said that there are three tentative workshops planned for this coming year in China, Latin America, and Puerto Rico.

Dr. Marcia Cruz-Correa commented that the interaction between scientists and journalists at the workshop was positive. Ms. Castro emphasized that journalists were encouraged to write stories based on scientific journal articles and expert consultations, instead of solely press releases.

Dr. Olopade questioned the workshop planning regarding local partners. Ms. Castro responded that there are collaborations with communications counterparts in the Ministries of Health in the participating countries. Additionally, there are communications with the Centers for Disease Control and Prevention (CDC) and the American Cancer Society (ACS), who are undertaking similar projects.

Dr. Kim Lyerly questioned the media feedback and improved communications between the United States and Latin America. Ms. Castro responded that this has been a concern. There is difficulty in getting representatives from news organizations to attend the workshop because they often are needed to cover multiple stories at one time, making them unavailable. If the workshop increases in popularity it is hoped that more participants will be able to attend.

Dr. Olopade said that many U.S. immigrants read newspapers from their home countries; therefore, the workshop could impact U.S. immigrants. Ms. Castro added that she believes efforts to improve scientific communication via journalism in the Americas are ongoing to raise awareness in the U.S.

International Activities of NCI-Designated Cancer Centers

Kalina Duncan

Dr. Trimble introduced Ms. Kalina Duncan by explaining that the NCI CGH created a draft report of the NCI-designated cancer centers international activities.

Ms. Duncan said that to generate the report, teleconferences and emails were used, and low- and middle-income countries were the foci. She emphasized that the report is not comprehensive.

Ms. Duncan said that three questions were asked of the cancer centers: (1) What are you doing and what are your international efforts? (2) Who are the individuals that NCI needs to know about? and (3) What are your recommendations for future directions in global cancer research? Information that is gathered includes the cancer center, country, foreign institution that is collaborating with the cancer center, project description, and mechanism of NCI funding.

Ms. Duncan described that the most common funding mechanisms are not those funded by the NCI/NIH; however, of those that are, NCI D43 awards are a common mechanism. Fogarty International Center (FIC) Capacity Building awards also are a common funding mechanism. A majority of projects are from the African region; China and India also are well represented.

Respondents indicated that the scientific recommendations for GCR include taking advantage of geographic variation in cancer centers, tailored interventions, and scientific capacity building, among others. Programmatic recommendations include using the existing infrastructure and models, creating global career tracks and funding, bettering cross-disciplinary efforts, and building collaborations. Future directions involve using the collected information optimally, stimulating international activities, and improving data gathering mechanisms.

Dr. Trimble commented that expanding the eligibility of pilot funding to include global health activities would benefit from political support.

Dr. Lyerly said that it will be important to capture the “voice” of international partners and learn where their interest lies for successful collaborative projects.

Evaluation Metrics for Training Programs in Global Health

Karl Poonai

Dr. Trimble said that using the appropriate metrics to evaluate programs is important. He introduced Mr. Karl Poonai to discuss this issue.

Mr. Poonai said that there are four types of evaluations: needs assessments, feasibility studies, process evaluations, and outcome evaluations. These evaluations can be used through a programmatic lifecycle (i.e., before, during, and/or after a program). Examples of evaluation questions include what should be the goals of a revamped training program, and what are the long- and short-term effects of a visiting scientist/fellow program.

There have been several recent evaluation activities at the NCI (e.g., Strengthening Capacity for Research for HIV-Associated Malignancies in Africa), and currently there is a prospective evaluation of

the Physical Science-Oncology Centers (PS-OCs). A PS-OCs evaluation would involve ongoing monitoring and feedback from the program onset.

Metrics for a D43 grant mechanism outcome evaluation might include enhanced research capacity, exemplified by the number of trainees, collaborations, and publications, and improved health outcomes, exemplified by enhanced clinical capacity, clinical training workshops, and prevalence/incidence rates.

Dr. Olopade questioned if there are metrics for how training programs have performed, and Mr. Poonai responded that it can be ascertained if there is such a benchmark. Dr. Joe Harford warned that international individuals are not captured in numbers of trainees funded through the NCI and that this is important for evaluations. He also said that individuals from low- and middle-income countries are underrepresented in NCI intramural training activities.

Global Palliative Care and Examples of NCI Activities

Joe Harford

Dr. Harford explained that the hospice program began in the United States in 1974 and became a medicare benefit in 1982; however, only one-third of dying Americans take advantage of this type of palliative care. In many areas of the world, the outlook is even more grim.

With findings published in *Cancer* in 2006, the Birmingham International Workshop on Supportive, Palliative, and End-of-Life Care Research focused on identifying research priorities. The most significant feature of cancer in low- and middle-income countries is late diagnosis. The implications of late diagnosis include lower cure rates, suffering, death, greater stigma, and a more pronounced need for emphasis on palliative care.

Breast cancer stage distributions indicate that the stage is skewed from early in the United States to late in Egypt. The United States and Africa have similar numbers of breast cancer-related deaths; however, in Africa a lower incidence rate is associated with more mortalities. Regardless of location, the symptoms of breast cancer can range from moderate to severe; however, there is a disparity in global palliative care distribution, with most of the palliative care workers being present in high-income countries, whereas most of the palliative care need is in low- to middle-income countries.

Dr. Harford said that palliative care can refer to symptom management and that 150 out of the 190 world countries have morphine restrictions. Pain relief often is regarded as the palliative care “flagship” and millions of people worldwide are not receiving pain relief.

There has been an effort to remedy this through a palliative care workshop by the Middle East Cancer Consortium (MECC), the first palliative care workshop in Palestine (Al-Sadeel Society for Palliative Care), and palliative care training across borders (e.g., Israel/Palestine and Turkey/Cyprus).

Muslim-majority countries have limited availability of pain relief. This is due to palliative care not being supported by healthcare because of issues surrounding stigma, fear, and ignorance. There are efforts occurring in India, Nepal, and Brazil that involve palliative care training, consciousness training, education, workshops, and increasing palliative care at many sites (e.g., INCTR PAX

Program, Leadership Development Initiative, and others). This is drawing increased awareness from government circles.

Dr. Harford explained that because individuals cannot be educated individually in palliative care the International Palliative Care Resource Center (IPCRC) was developed and a website created to link users to available information on palliative care (www.IPCRC.net).

Dr. Harford answered a question from a participant by explaining that religion can play a role in Muslim-majority countries in patients not receiving palliative care. Some Islam adherents believe that pain is atonement, although this belief is not restricted to Islam. Additional hurdles are a general fear of addiction and that pain medications are governed by drug enforcement agencies.

Dr. Judith Kaur commented that success has been achieved in making hospice and palliative care non-synonymous, and the NCI needs to examine where palliative care fits in their “cancer portfolio.”

Responding to Dr. Karen Meneses’ question concerning the high level and quality of palliative care in Kerala, India, Dr. Harford explained that communism has worked well in that state. Kerala also has a high literacy rate and had an influential individual who championed palliative care.

Research Capacity Building in Latin America: Latin America Cancer Research Network Model *Jorge Gomez*

Dr. Jorge Gomez said that the United States-Latin America Cancer Research Network (US-LA CRN) has developed a good model for capacity building in Latin America, and created four guiding principles. These principles encompass providing new insights, fostering collaborations based on mutual respect (i.e., cultural competence), initiating research projects to advance science, and building research capacity.

The operating principle for this model is to develop sustainable research capabilities in basic, translational, and clinical cancer research; education and training; and advanced technologies and capacity building.

The US-LA CRN model enables cancer research collaboration between the United States and Latin America and continues to grow. The model’s governance is composed of a steering committee based on Ministries of Health from countries that oversee the US-LA CRN. The formation of multidisciplinary groups in this way is new.

Dr. Gomez described the first research protocol that was developed for “Molecular Profiling of Stage II and III Breast Cancer in Latin American Women Receiving Standard of Care Treatment (MPBC Study).” The primary and secondary objectives were defined, as well as the breast cancer profiling that would be utilized. The benefits of the MPBC study are improved breast cancer diagnosis, improved understanding of the correlation of breast cancer molecular profiles with response to therapy, collection of well-annotated biospecimens, and creation of a model for systematically conducting cancer research. Success in the MPBC example depended on an available infrastructure to work from and the involved countries being middle income. For success, harmonization of different fields was necessary, along with procedure consensus and the development of manuals in multiple languages.

A primary component of the MPBC study was the standardization of pathology and biorepository procedures. These data are stored in OpenClinica™, an idea that was generated via consensus and the ability of all involved collaborators.

Dr. Waun Ki Hong questioned if the molecular profiling of breast cancer is limited to women who receive standard treatment. Dr. Gomez affirmed this and said that standard care is managed by health care systems in individual countries. Dr. Olopade confirmed that all individuals receive the same standard of care and that there are absolute quality control (QC) standards.

Responding to Dr. Kevin Cullen, Dr. Gomez said that all the data are housed at the NCI and these data can be transferred to countries as needed; however, the data are not intermixed and only the NCI has the capability to examine data from all the countries.

Dr. Kaur questioned the bioethnics and patient consent processes in the modules, and Dr. Gomez responded that they all are compliant with current Institutional Review Board (IRB) requirements. Some countries have multiple layers of bioethics special requirements.

Discussions and New Business

Dr. Trimble expressed enthusiasm for the GCR progress in Latin America and said that the progress already made can assist in the establishment of research networks across the world. He said that a planned meeting with external stakeholders on March 13–14, 2012, will elicit advice on research priorities for the NCI. More than 100 registrants are external to the NCI, and the feedback from this meeting will be presented at the next GCR subcommittee meeting.

Dr. Trimble acknowledged that Dr. Brenda Edwards prepared a presentation for the subcommittee meeting, but due to time constraints, it will be presented at the next GCR subcommittee meeting.

Future Meetings

The following were suggested as agenda topics for future meetings:

- Report on the advice of external collaborators for NCI research priorities—Dr. Trimble
- Presentation on “Tumor Registries—NCI’s Role in International Activities”—Dr. Edwards

The Subcommittee meeting adjourned at 8:25 p.m. EST.

Dr. Olufunmilayo Olopade Date
Chair

Dr. Edward Trimble Date
Executive Secretary