

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

Hyatt Regency Bethesda Hotel
Old Georgetown Room
1 Bethesda Metro Center
Bethesda, MD
June 24, 2012
5:00 p.m. – 6:30 p.m. EDT

SUMMARY

Subcommittee Members

Olufunmilayo Olopade, University of Chicago (Chair)
Kim Lyerly, Duke University
Karen Meneses, University of Alabama at Birmingham

NCAB and BSA Members

Francis Ali-Osman, Duke University
Donald Coffey, The Johns Hopkins University
Chi Dang, University of Pennsylvania
Kathleen Foley, Memorial Sloan-Kettering Cancer Center
Stan Gerson, Case Western Reserve University
Mary Hendrix, Northwestern University
Jim Omel, Retired Physician

Other Participants

Brenda Edwards	Mostafa Nokta
Mark Fleury	Hasnaa Shafik
Annette Galassi	Shamala Srinivas
Daniella Gerhard	Lisa Stevens
Brenda Kostelecky	Darlene Summers
Douglas Lowy	Bhadrasain Vikram
Cathy Muha	Jennifer McCulley, Rapporteur
Kimberly Myers	

Welcome and Opening Remarks

Dr. Olufunmilayo Olopade, Subcommittee Chair, welcomed meeting participants and thanked the NCI staff for their efforts. NCAB members introduced themselves.

Global Cancer Health Registries

Brenda Edwards

Dr. Olopade introduced Dr. Brenda Edwards, who described the NCI's role in global cancer health registries. Dr. Edwards explained that the NCI focuses on population-based cancer registries, noting

that these data are accessed by a variety of users, including researchers, clinicians, public health officials, patients, and legislators.

NCI's Surveillance, Epidemiology, and End Results (SEER) Program is a research resource, contributing data to pooled registries such as the Cancer Incidence in Five Continents (Ci5) and generating reports. Key elements of the SEER program include case ascertainment and a multi-tiered data system that collects demographic, disease, and survival information. SEER also incorporates national mortality data and Census information to generate statistical data, reports, research databases and linkages, and analysis tools. In addition, NCI Supports the All Ireland NCI Cancer Consortium, Middle East Cancer Consortium (MECC), and the North American Association of Central Cancer Registries (NAACCR), which functions to develop and promote uniform standards for registries, including a certification process for the quality of data.

The International Association of Cancer Registries (IACR), founded in 1966, fosters the exchange of information among registries. Headquartered in Lyon, France, the IACR represents approximately one-fifth of the world's population through its registries. Global cancer information available at the IACR through *CANCERmondial* includes access to statistical data, registries, and analytic tools.

Dr. Edwards explained that the global burden of cancer is projected to rise substantially by 2030, with developing countries shouldering much of the burden. She cautioned that incidence estimates, however, do not reflect true incidence rates. Cancer registries may cover subnational areas, and estimates may not be comparable over time due to improving data quality and coverage.

Population-based cancer registries are important for cancer control and form the basis for research. Challenges exist, however, with global cancer registration in low- and middle-income countries (LMIC). The inadequate number of pathologists and lack of diagnostic facilities results in long reporting delays and low verification rates. Survival is poor and formal death certification is deficient. Limited population data, difficulty transporting patients to hospitals, insufficient staff and information technology support, and lack of priority from Ministries of Health (MoH) also contribute to the problems facing cancer registration in LMIC.

The Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries (GICR) is a partnership led by the IARC to promote change through advocacy. The GICR works to create centers of expertise ("hubs") around the world that provide regional expertise and support, increased access to training, additional research prospects, and networking opportunities. The first hub, launched in Mumbai, is now operational, and future hubs are to be located in Turkey, Africa, and Latin America.

Dr. Edwards summarized the importance of cancer registration, noting that tumor registries provide opportunities for surveillance, cancer control, and research. The NCI is engaged globally to develop approaches and tools, share expertise, and recognize the human and cultural component of global collaborations to improve global cancer outcomes.

Dr. Mary Hendrix asked whether training was offered to assist with Institutional Review Board (IRB) approval to access registry data. Dr. Edwards noted that some non-identifiable data could be accessed and analyzed without needing IRB approval. The largest barrier is not IRB approval, rather confidence in the quality of data.

Dr. Francis Ali-Osman affirmed that the hub concept was a good idea. Dr. Edwards elaborated that the regional hub in Mumbai would function to seed other hubs throughout the region in countries such as Japan and China. Supplementing the efforts of the IARC headquarters, the hubs provide additional resources to assist with registry activities. Dr. Edwards explained that the IARC regional hub plan includes evaluations. To become a hub, the site must demonstrate sustainability toward the initiative, and partnership efforts garner high marks.

Dr. Olopade noted that because resources are allocated based on cancer incidence estimates, the lack of quality global cancer statistics is a real concern. She questioned the estimated 21% global coverage in terms of developing and developed countries. Dr. Edwards estimated that 5 to 10 percent of the coverage was in Africa but the quality may be sub-optimal. She explained that forming quality registries that are representative of regions is an important step, as those registries can grow over time. Even now, expected cancer death rates are generated from modeling. More registries with better coverage and more reliable estimates are needed.

Dr. Douglas Lowy, Deputy Director, asked Dr. Edwards about the trajectory of registry coverage and quality over the past 20 years. Dr. Edwards replied that the number of registries and countries represented is not very different. Regarding data quality control issues, NCI is working to provide training and support registry development.

A participant suggested that engaging clinicians in registry activities by providing mortality data might help to improve the MoH's prioritization of cancer registries. Dr. Edwards agreed that including survival data in cancer registries is important.

Dr. Olopade said that the Center should prioritize actions to make an impact in terms of their declared mission, and she solicited ideas about what the NCI can do. Dr. Edwards noted that North American registries progress rapidly by convening to interact and share ideas. A key point will be to leverage resources that already exist, because the IARC and NCI cannot accomplish everything alone. Dr. Lisa Stevens suggested that a meeting could be convened to ascertain which organizations and institutions are engaging in what efforts around the world.

Dr. Lowy stated that cancer registries, outcome data, and a cancer plan are three important components of the Center. He cautioned that the sustainability of a project over time must be considered carefully.

In response to a question, Dr. Edwards clarified that data usually are reported in 5- or 10-year intervals. For example, Globocam data are published in aggregates to create the best quantitative picture within the limits of the data.

Dr. Olopade reminded attendees of the MECC and Ireland Cancer Consortium as examples of where the NCI invested funding to train scientists locally. NCI employed a comprehensive approach to the Ireland consortium, and now Ireland has a self-sustaining registry with measurable research progress.

Dr. Ali-Osman commented that a good registry is critical to policy making and encouraged the NCI to rank this as a high priority. Dr. Coffey noted that because funding is universally limited, it is important to be transparent about the tradeoffs. Dr. Olopade agreed that one of the most important outcomes for this subcommittee meeting is to determine what funding the new Center means for the NCI local and global cancer research.

Dr. Donald Coffey suggested contacting wealthy countries to help finance projects. Dr. Olopade concurred, mentioning several international partnerships that provide funding to LMIC to advance cancer research.

Update on NCI Center for Global Health

Lisa Stevens

Dr. Stevens provided an update on the NCI Center for Global Health. In the 4 months since the inaugural stakeholder meeting on March 13–14, 2012, the Center has been working to set priorities. More than 150 stakeholders attended the 2-day meeting to provide input into the strategic direction of the Center. Dr. Varmus began the inaugural meeting by imparting high-level goals, stating that the Center should identify research activities that are likely to have an impact on the global cancer burden, evaluate existing capabilities, and build solid partnerships around the world. At the stakeholder meeting, Dr. Varmus reiterated that NCI efforts must maintain a research component.

Prior to the meeting, Drs. Varmus and Trimble prepared a white paper outlining six priorities for global health and cancer research: (1) cancers associated with chronic infection; (2) cancer control planning and implementation; (3) common risk factors for non-communicable diseases; (4) ecological-niche cancers; (5) building the infrastructure for cancer research and training; and (6) strengthening partnerships in health research.

At the meeting, stakeholders discussed those priorities and reached consensus on several points, including the use of domestic research as a starting point for global outreach. Stakeholders also agreed that training and mentoring young researchers is a valuable investment. Developing new global partnerships, pursuing novel funding mechanisms such as the D43 partnership, and defining global implementation strategies that leverage existing expertise and infrastructure were other points of consensus. A useful implementation strategy might be to establish regional Centers of Excellence.

Dr. Stevens explained that to date, the Center's only source of funding has been the budget of the four offices that comprise the Center. She reminded participants that many global activities exist outside of the Center; communicating internally and with partnering institutions to avoid duplication of efforts is important. Even without a large budget, NCI's ability to serve as a convener can bring global players to the table to develop consensus for priority actions in specific regions.

After reviewing the stakeholder input, gathering additional comments from NCI Divisions, Centers, and Offices, and reviewing legacy Center for Global Health programs, the strategic planning team developed draft mission and vision statements and confirmed priority areas. The draft mission statement reads: "The mission of NCI's Center for Global Health is to reduce the global burden of cancer by supporting cancer research and cancer control, leveraging partnerships, assessing research needs and efforts, and catalyzing information dissemination and capacity building worldwide." The draft vision statement for the Center is: "NCI's Center for Global Health will be a catalytic force in global health through its tangible contributions to cancer research and cancer control worldwide, realized by ongoing coordination, collaboration, and communication with a diverse range of stakeholders and partners in order to further our mission to reduce the global burden of cancer." Priority areas include supporting research, leveraging partnerships, monitoring research efforts, and catalyzing training, information dissemination, capacity building, and cancer control.

Dr. Stevens outlined the next steps for the Center, which include developing action plans during the summer, reviewing the competencies of the staff to identify positions to hire and retraining opportunities. The Center will submit a budget request to Dr. Varmus and pursue granting authority for the Center to release request for applications (RFAs). Working closely with NCI Divisions, Centers, and Offices, the Center will pursue strategic planning for global health and global cancer research.

A participant suggested using a sliding scale to match country funds based on the gross domestic product (GDP). Dr. Stevens agreed with the premise, noting that in the past week, the Center had signed a letter of intent to collaborate with Peru, the sixth country to agree to contribute funds for research in the Latin American Cancer Research Network. Brazil is another country that provides research funds.

Dr. Stevens mentioned that large gains can be realized by identifying existing research infrastructure and making small investments to shift the focus to cancer research. Dr. Ali-Osman concurred, noting that some countries already have partnerships that link chronic infections and cancer. Dr. Olopade and other participants discussed additional partnerships to leverage, such as the Gates Foundation. Dr. Hendrix suggested Research America as a natural partner for NCI.

Dr. Bruce Chabner queried Dr. Stevens regarding the current budget of the Center, which has not received funds since the Center's creation. Now that a strategic plan has been formed, funding is easier to justify. Dr. Chabner cautioned that the Center is presented to the public as a priority action and should be funded as such. Academic institutions are moving forward with research agendas without waiting for the NCI to procure funding. Although researchers could use existing funding mechanisms for global health initiatives, the funding climate is very competitive.

Dr. Chi Dang asked whether the Center had collected data on NCI- and academic-supported cancer initiatives. Dr. Stevens replied that 33 Cancer Centers have reported their global actions. The participants discussed the utility of mapping other global health initiatives, such as AIDS consortia efforts PEPFAR, USAID, etc. In response to a question, Dr. Stevens noted that the four priority areas could be divided into five if further consideration deemed it necessary.

Dr. Lyerly remarked that the survey of existing global health initiatives would make a great appendix. He mentioned that through his experience in India and Pakistan, he was surprised that the opinions of the researchers and clinicians within the countries were not mentioned in reports or discussions. It is important that the United States does not prescribe priorities for other countries, but rather that the countries' own priorities drive the research agenda.

Dr. Olopade thanked the meeting attendees for their participation. The Subcommittee meeting adjourned at 6:30 p.m. EDT.

Dr. Olufunmilayo Olopade Date
Chair

Dr. Edward Trimble Date
Executive Secretary