

**Department of Health and Human Services
National Institute of Environmental Health Sciences
National Cancer Institute**

**Minutes of the Research Translation, Dissemination, and Policy Implications
Subcommittee of the Interagency Breast Cancer and Environmental Research
Coordinating Committee**

January 10, 2012

The Research Translation, Dissemination, and Policy Implications (RTDPI) Subcommittee of the Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) was convened for a meeting on January 10, 2012 at 3:00 PM EST via conference call. The Chair of the subcommittee was Jeanne Rizzo, R.N. of the Breast Cancer Fund.

Subcommittee Members Present

Beverly Canin
Ysabel Duron
Ronda Henry-Tillman, M.D.
Karen Miller
Marcus Plescia, M.D., M.P.H.
Jeanne Rizzo, R.N.

NIH Staff Present

Jennifer Collins, M.R. (NIEHS)
Christie Kaefer, M.B.A., R.D. (NCI)

Guests

Connie Engel, Ph.D. (Breast Cancer Fund)

I. BACKGROUND

The Interagency Breast Cancer and Environmental Research Coordinating Committee (IBCERCC) is a congressionally mandated body established by the National Institute of Environmental Health Sciences (NIEHS), in collaboration with the National Cancer Institute (NCI). This Committee is comprised of 19 voting members, including representatives of Federal agencies; non-federal scientists, physicians, and other health professionals from clinical, basic, and public health sciences; and advocates for individuals with breast cancer.

The Committee's primary mission is to facilitate the efficient and effective exchange of information on breast cancer research activities among the member agencies, and to advise the NIH and other Federal agencies in the solicitation of proposals for collaborative, multidisciplinary research, including proposals to further evaluate environmental and genomic factors that may be related to the etiology of breast cancer. The Committee serves as a forum and

assists in increasing public understanding of the member agencies' activities, programs, policies, and research, and in bringing important matters of interest forward for discussion.

The objectives of the RTDPI Subcommittee of the IBCERCC are integrated and dependent on the objectives and activities of the other Subcommittees of the IBCERCC and include the following: to identify successful models as well as gaps in research translation and dissemination, to make recommendations to improve both with an emphasis on breast cancer and the environment; to make policy recommendations to that end; to address areas in which the scientific evidence on breast cancer and the environment supports precautionary public health policy; and to identify methods to expand public participation in the research translation and dissemination processes to more effectively involve patient advocacy and community organizations, environmental health, environmental justice as well as practitioners in public health and health care delivery.

The tenth meeting (conference call) of the RTDPI Subcommittee took place on January 10, 2012. During this meeting, the upcoming IBCERCC meeting at NIEHS was discussed, along with the draft chapters of the report. The minutes from the December RTDPI conference call were approved.

II. DISCUSSION

IBCERCC Report

The RTDPI Subcommittee discussed the status of the State of the Science (SOS) and Research Process (RP) sections of the IBCERCC report. Jennifer Collins said the SOS section would be undergoing major revisions over the next week. The RP Subcommittee had a conference call last week and they will add some discussion of Federal agencies currently missing from their section of the report. The RP Subcommittee will also be working on their discussion of cross-agency collaboration.

Ysabel Duron said she read most of the report and tried to keep the viewpoints in mind of the general public, and someone not impacted by the topic (e.g. in Federal agencies, Congress, media organization) to try and imagine the report's impact. Ysabel felt something was needed, maybe a one page document to accompany the report that will catch the attention of a cross-section of people. Such a document needs to be "hard hitting," specific, and engaging.

Additionally, Ysabel stated that information about understudied populations and exposures at young ages need to be key points in the report. For example, she did not see information about understudied populations until page 68 in the report. Ysabel did not feel there is currently anything "hard-hitting" in the report (e.g. banning certain chemicals) and the recommendations are not bold.

In response, Jeanne Rizzo said the Executive Summary has not yet been written and any collateral documents needed to supplement the IBCERCC's report, and an overall communications plan, will be discussed at the upcoming meeting at NIEHS. When the IBCERCC develops its overarching recommendations to be made in the Executive Summary,

these will also need to get worked into any collateral documents that are to be developed. Also, the IBCERCC is still trying to find its collective voice. Each section of the report still has a different voice right now. The tone does need to be one that will make readers take the report seriously. Beverly Canin felt that until the Committee members can see an outline or draft of the Executive Summary, it is impossible to know what might be missing, but she agreed that it needs to be strong. Jeanne clarified that Kathy Brown-Haumani, of the Scientific Consulting Group, Inc., is editing the entire report.

Karen Miller asked if there is an opportunity to pull all the overarching statements together at the beginning of the IBCERCC report, in addition to the Executive Summary. Jeanne said that to the best of her knowledge, there will be an introduction that provides background about the Committee and its members and an Executive Summary containing the Committee's recommendations. There have been various approaches discussed over time for how best to pull the report's recommendations together.

Jeanne indicated that the look and tone of the report will be part of the in-person meeting later this month. RTDPI members do have thoughts on what some of the imperatives are. A "frozen" version of the draft report will be circulated in the near future to all IBCERCC members to review prior to the next meeting. Jennifer said that all IBCERCC members will be asked to comment on their overall impression of the report, what they think the significant gaps are, areas that need more clarity, the audiences this report will reach and/or impact, etc. Jennifer will send an email with the list of questions to the RTDPI members. In order for everyone's views to be heard, everyone will be asked to talk for a few minutes. Jeanne recommended that if there are aspects of the draft report that RTDPI members do not like, it would be constructive to offer an alternative solution.

To date, there have been 18 drafts of the IBCERCC report. Some words have been changed occasionally for tone. The goal is to be encouraging, not prescriptive, but there haven't been any recommendations that have been stepped away from. Kathy suggested added more references to support various recommendations. Jeanne asked RTDPI members to think about whether they feel the Subcommittee has made the case for and supported its recommendations.

Connie Engel described some of the areas of the RTDPI sections that have changed. The discussion of research translation has been tightened up and the information about research dissemination has been dramatically revised, with new references added. The other changes have been primarily reorganization, with some new paragraphs occasionally added.

Jeanne said she is still not certain how the recommendations will be presented, e.g. at the end of each section or within each section, where the narrative supports the recommendations. Additionally, it is possible that recommendations that cross multiple sections could be reworked so they cross over the entire report. Jennifer confirmed that the format for presentation of recommendations has not yet been finalized by the IBCERCC's leadership. Beverly said she really liked how the recommendations fit within the text in terms of the justification and flow. If an easier way to access the recommendations is needed, she suggested they could also be summarized somewhere in the report, but when contained in the text, they strengthen the

discussion. Connie thought that the RTDPI Subcommittee's first recommendation is really broad and may need to stay at the beginning or end of the RTDPI section, but others could follow the narrative. Jeanne suggested that individual preferences regarding presentation of recommendations could be made during the in-person meeting in a few weeks.

Beverly pointed out that a few sections of the RTDPI text contained bullets whereas other areas are more descriptive and she recommended that a consistent approach be used throughout the text.

Jeanne asked if there were any concerns, worries, support, etc. for the current version of the report and its recommendations? Ysabel asked about Table 4.1 and whether there is any translational research related to minorities? Jeanne mentioned that Michele Forman has asked the SOS and RP Subcommittee to look at this issue specifically. For example, more attention will be given to the Sister Study, which is actively recruiting minorities, as did the Breast Cancer and Environment Research Program. Regarding T4, there may also be another example related to premenopausal African-American women. If others have ideas, they were asked to share them.

Ysabel also noted there are a lot of references to communities and environmental projects, but nothing related to cultural and linguistic models. For this concern, and her previous one, Ysabel felt we cannot easily identify examples because they are understudied areas, and this needs to be highlighted throughout the entire IBCERCC report.

Karen thought that the RTDPI Subcommittee members may need to go back and make sure the SOS recommendations are threaded through the RTDPI sections.

Jeanne thought the "precautionary approach" is well-supported, but there is likely to be discussion during the meeting at NIEHS regarding the "precautionary principle" goal. One goal for the in-person meeting is that we do not leave the meeting with someone in strong disagreement regarding some aspect of the report. We want all the IBCERCC members to be able to get behind the report. The wording in some places in the policy section has been toned down to try to accomplish our goals without being inflammatory.

Beverly said she felt the SOS sections are still lacking in the area of prevention. Jeanne said Michele really liked the recommendation to develop a national strategy and wants to incorporate that elsewhere in the report. Marcus Plescia said he really liked that recommendation too and if the IBCERCC is able to achieve that, it will really have accomplished a lot.

Another task that the IBCERCC members will be asked to do is to put the report's current recommendations into a priority order. This will help create a better understanding of what are the most important recommendations and whether any can be woven together in all the report's sections. There will need to be some prioritization because not all recommendations can be included on the first page of the report.

The NIEHS Director, Dr. Linda Birnbaum, may not be able to participate in the meeting later this month in North Carolina, but she will leave some remarks to be shared with the group,

including the appropriateness of the policy-related content. There still may be one or two people who disagree with this point of view.

Regarding the timelines, there have been many iterations of these and lots of thinking. Jeanne thanked Karen, Beverly, and Connie for their work on this. It started as a timeline of advocate involvement, but has changed and is now broader. Beverly said she is still unclear about the overall theme of the timeline, e.g. is it focused on research related to breast cancer and the environment? As a result of her uncertainty regarding its overall purpose, Beverly said she is not sure how to edit the current version of the timeline. Ysabel said that as a generalist, she doesn't have a strong sense of the history of breast cancer. The timeline includes references to the environment, advocacy, policy, etc., and she doesn't know how to edit it down either. Karen suggested weaving in key achievements to see where they intersect with information that is already there. This could help illustrate how the field has progressed or how it has not progressed far enough. Beverly thought it would be wonderful if the "roadmap" could be woven through the report graphically. Karen added that whether or not the timeline is used in the final report, the process of creating it helped pull together important details. Jeanne mentioned there has been some discussion about including a timeline as an appendix, and maybe this could be discussed more during the in-person meeting. Jeanne also mentioned that Gwen Collins thought an important aspect to convey was the strong role advocates have played over time that research initiatives have been one of the results of advocate involvement.

During the in-person meeting, Jeanne asked RTDPI members to take notes on the IBCERCC members' overall impressions of the report, which will be shared during the morning session on the first day. There will be a process for triaging the recommendations so that the most discussion time will be spent on recommendations that IBCERCC members have concerns or differing opinions about. Topics for the second day of the meeting will include discussion of the overall look and feel of the report, how to present timelines, the communications planning and report clearance processes, reviewers, and action items. Jeanne mentioned part of the discussion will focus on how to keep the report "alive" after its release. Jeanne also shared that Shelia Zahm recently retired from the NIH, but she will be at the in-person meeting.

The final topic of discussion during the RTDPI conference call was proposed stories to be included in the IBCERCC report. Jeanne thanked Ysabel for submitting the first story about a survivor. Ed Kang in the NIEHS Office of Communications also appreciated the photo of the survivor that Ysabel forwarded because it helps put a human face on the story. Karen said she will be providing three more stories next week, one of which is also a survivor. Jeanne said she also has three confirmed stories and two "maybes." One of Jeanne's confirmed stories is from a scientist. Beverly said one of her two stories will be from a clinician.

Action Items, assignments, and due dates:

- Prior to the in-person meeting (January 23-24, 2012), all should:
 - Review the entire draft IBCERCC report.
 - Come prepared to respond to the questions about the report that Jennifer Collins sent via email and discuss their priorities for the report's recommendations,

- Be prepared to offer alternative ideas to any areas of the report that concern you or that you disagree with, and
- Copy Ed Kang (edward.kang@nih.gov) on any email submissions of stories for the IBCERCC report.

CERTIFICATION

I hereby certify that, to the best of my knowledge, the foregoing minutes and attachments are accurate and complete.

/Jeanne Rizzo/

Jeanne Rizzo, RN

Chairperson

Research Translation, Dissemination, and Policy Implications Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

/Gwen W. Collman/

Gwen W. Collman, PhD

Executive Secretary

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)