

**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**

October 11, 2011

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 October 11, 2011 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.
Shelia Zahm, Sc.D.

NIH Staff Present

Dacia Beard, M.P.H. (NCI)
Jennifer Collins, M.R. (NIEHS)
Christie Kaefer, M.B.A., R.D. (NCI)
Liam O'Fallon, M.A. (NIEHS)

Guests

Martha Diaz (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 ninth meeting (conference call) of the RTDPI Subcommittee took place on October 11, 2011. During this meeting, the Subcommittee's draft chapters for the IBCERCC report were discussed, along with the draft Executive Summary for the full report.

II. DISCUSSION

Communication and Dissemination Update

The RTDPI Subcommittee reviewed the most recent draft of the communication and dissemination content. The diabetes example could be moved to an appendix if needed. Ysabel commented that there is a need to identify who is being targeted in communications planning before dissemination activities begin because different approaches may be used depending on who the audience is. Beverly and Liam agreed but questioned whether this concept is clearly articulated in the current draft. Jeanne asked that all comments on this section be submitted by October 19th. Jeanne also wants to make sure that the Subcommittee responds to feedback provided by the full IBCERCC during the September in-person meeting.

Jeanne asked the Subcommittee whether they would like to combine this section with the section on research translation because of some previously identified areas of overlap. Karen agreed with the proposal. No objections were raised. Once the communication and dissemination

content is fully developed, Connie will merge the two sections. Karen asked for clarification on the process for merging the two sections, in particular to make sure that some of the narrative they have worked on is not lost in the process.

Although Ysabel acknowledged that some of the key communication themes are reflected in the draft Executive Summary circulated electronically over the past week amongst the full IBCERCC, the group discussed concerns that the Executive Summary does not fully capture the scope of comments/key points summarized at the end of the in-person meeting. RDTPI members will provide feedback individually and as a group on the Executive Summary. The RTDPI members will also strive to develop solid report sections that can be used as a source of information for the Executive Summary.

Regarding the communication and dissemination recommendations:

- For the recommendation regarding a communications toolkit, consider adding a citation with examples of toolkits.
- Karen recommended the addition of a recommendation calling for Federal agencies to be responsive to community concerns. Additionally, she suggested this should be a key theme throughout all RDTPI sections and the Subcommittee could encourage the other IBCERCC Subcommittees to include this in their chapters and recommendations too. Jeanne added that use of bi-directional communication as much as possible, not just pushing information out to the public, is probably in the text somewhere, but not currently a specific recommendation.
- Beverly thought the wording needs to be stronger, e.g. “requires” instead of “encourages”, etc. Ronda agreed that the Subcommittee needs to be very direct about what it wants and Karen also supported the use of strong language throughout the text. Shelia added that at the in-person meeting, the concerns raised had to do with who was being required to do certain things, for example, the full committee seemed to find it acceptable to require things of funding agencies, but was hesitant to require certain things of principal investigators in grant applications.
- Liam recommended placing a greater emphasis on need for skilled communicators. He felt there is often too much emphasis on degrees vs. skills. Liam also recommended the inclusion of evaluation in the recommendations to help determine whether communication strategies and dissemination activities are successful. Ysabel supported the need for evaluation as a part of communication plans; it proves the value of communication and dissemination. Jeanne asked whether there are models for determining changes in behaviors, policies, etc. Liam will forward the most recent version of the PEPH Metrics Manual.

Jeanne asked the NIH staff to pass along Subcommittee concern that planning should begin as soon as possible for a process to publicize the IBCERCC report once it is finalized. Jenny will be meeting soon with the NIEHS Office of Communications on this topic, and they intend to coordinate with NCI. NIH staff will also follow-up as soon as possible with Debbie Winn and Gwen Collman to identify additional planning needs/actions.

Ysabel also followed up to the request made during the in-person meeting and provided suggestions on how the IBCERCC could weave the theme of inclusiveness throughout the report, e.g. the Executive Summary, the Research Process content, and the State of the Science content. Shelia, Beverly, Karen, Jeanne, and Connie provided input on the content as well. Questions that the other Subcommittees should consider include whether there are enough funded minority researchers and the importance of engaging minority populations in research. Also, what percent of Federal research dollars spent on breast cancer and environmental research are used to study populations representing different race/ethnic groups? Jenny can share the RTDPI questions with the other IBCERCC Subcommittees.

Research Translation Update

Since RTDPI members would like to merge the research translation chapter with the communication and dissemination chapter, Jeanne will work with Connie to develop a new timeline that incorporates this step; however, members can still provide feedback on the research translation content. Beverly stated she thought the two sections should be merged and she hopes the next version from Connie will include feedback she submitted earlier today.

Beverly specifically wanted to review the draft matrix and Shelia's previous suggestions for the format. She acknowledged some previous e-mail discussion of using symbols to represent the degree that various programs listed in the matrix incorporate various criteria; however, Beverly did not think it was appropriate for the RTDPI Subcommittee to try to evaluate various programs. As a guide to what the final matrix might look like, she presented a draft which included some of the previously identified "model programs" and indicated in each of the columns whether a program did or did not include each element. Jeanne asked for clarification regarding the goal of the matrix in relation to the report. Beverly said it started as a way to identify model programs to inform the report narrative and was originally intended only as a working document. The matrix does not necessarily need to be included in the report, but could serve as a reference to readers.

Beverly followed up by asking RTDPI members whether the matrix should be included and if so, whether it should list only "model programs"? Shelia thought it could be useful to include the matrix. Jeanne asked if we might want to include some funding details too. Christie pointed out that based on the current title of the matrix, the NCI CARRA program doesn't belong in the matrix because it is an advisory panel, not a research program. Beverly clarified that the original purpose of the matrix was partially to identify various programs that included advocates. Jeanne added that there are a variety of ways advocates can be involved and Shelia felt that it is still possible to learn from programs that do a limited number of functions well. Karen thinks the matrix should list model programs, describe those models, and critique the models. Karen added that specific examples could be woven through the narrative. Jeanne thought the criteria in the matrix were fabulous and recommended that the narrative be reviewed to ensure they are reflected there too. Additionally, they could potentially be considered as criteria for funders. Shelia did raise a concern that readers may focus too much on what programs were included or excluded and whether the information is completely accurate; however, readers would probably be less likely to scrutinize examples in the narrative as closely. When Jeanne asked if any

RTDPI members had any strong arguments to offer for Beverly to continue working on the narrative, none were shared. The conversation continued with no clear opinions voiced one way or the other. Beverly offered to add all of the original programs to the new matrix so that it could be reviewed again during the next meeting. Ronda likes the matrix but agreed that all organizations can't be listed and if it is kept, a disclaimer should be added that it is not meant to be completely inclusive. Jeanne recommended reviewing the research translation narrative to ensure the main points are included in the text in the event the matrix is not used in the IBCERCC report. Ysabel asked Beverly if she could do a search to see if there are any organizations focused on minority groups that could be included.

Policy Update

Shelia revised the draft text to incorporate the feedback she has received to date. Modifications included:

- In the introduction, a connection was made between policies and how they affect the availability of data for research purposes.
- Throughout the document, instead of making general references to policy, discussion specific to breast cancer and the environment was used whenever possible.
- An explanation was added about why personal care products are important in relation to breast cancer risk.
- Discussion was added about high volume chemical production and exposure to chemicals. Jeanne recommended also adding some discussion about chemicals that are a significant hazard even if not many people are exposed, e.g. workers in asbestos plants.
- Minor wording changes related to interagency coordination and added information about post-marketing surveillance because of problems related to DES and other pharmaceuticals.
- Revisions to community participation section to incorporate feedback from Marcus.
- Added background information about what EPA has done related to confidential business information. Jeanne indicated there may be some more information that could be used from the "Right to Know" document she sent to Shelia. Not everyone knows how to submit Freedom of Information Act (FOIA) requests.
- Although Shelia did not specifically use the term "precautionary principle" she moved the discussion of this to the beginning of the policy text based on a recommendation from Gwen. Shelia used other language to describe the principle, without watering down the recommendations, because use of the term "precautionary principle" can be an immediate turn-off to some, even if they agree in general with the statement.

Shelia wasn't sure if there should be a conclusion section for the policy chapter. Jeanne recommended that each section have a concluding sentence or two. If the RTDPI Subcommittee can't develop conclusions, it's not reasonable to expect anyone else to be able to. These sentences could be used as "pull out sentences" that could be included in the Executive Summary.

IOM Report

Jeanne asked NIH staff if a date has been identified for the full IBCERCC to have some follow-up discussion after the release of the IOM report. NIH staff confirmed that no dates have been identified. Jeanne thought it would be important to discuss how the IOM report will inform IBCERCC and whether there are any items in the IOM report that the IBCERCC should address. The RTDPI Subcommittee will be having a call the day before the IOM report release, which is scheduled for December 7th. Debbie Winn and Connie Engel will be attending the meeting in San Antonio, and Karen Miller may attend. Jenny will ask Gwen and/or the NIEHS Office of Communications if it will be possible to obtain an advance copy of the report for discussion and to assist with coordination of the NIEHS and NCI response (if needed).

Action Items, assignments, and due dates:

- Feedback requested by RTDPI members on draft report sections by following dates (please send to Connie):
 - Communication and dissemination - October 19th
 - Policy October 19th
 - Final matrix and all appendices - October 21st
 - Research translation - October 26th
- Jeanne/Connie to revise timeline based on plan to merge sections on communication and dissemination with research translation.
- NIH staff to pass along Subcommittee questions/concerns:
 - Need to schedule a full IBCERCC conference call to discuss IOM report before or soon after report release date (December 7, 2011)?
 - Planning should begin as soon as possible for a process to publicize the IBCERCC report once it is finalized.

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

Research Process Subcommittee

Interagency Breast Cancer & Environmental Research Coordinating Committee

Proper signatures

Treat as signed, § 1.4(d)(2)