

**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**

**September 13, 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 September 13, 2011 at 1:00 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, MD  
Karen Miller  
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**

Connie Engel, Ph.D. (Breast Cancer Fund)  
Melissa Palmer, M.P.H. (CDC)

**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 eighth meeting (conference call) of the RTDPI Subcommittee took place on September 13, 2011. During this meeting, past meeting minutes were discussed, along with the Subcommittee's draft chapters for the IBCERCC report. The minutes from the August meeting were reviewed and approved with corrections.

## **II. DISCUSSION**

### ***Minutes***

Minutes approved. No additional corrections were provided by Subcommittee members to the August 17, 2011 RTDPI minutes.

### ***Policy Update***

Since the last call, Shelia did the majority of the drafting, incorporating materials sent by Marcus Plescia. The two draft documents include a draft chapter, "Policy Matters," and an annotated bibliography. Jeanne requested that Shelia present the policy-related material at the IBCERCC face-to-face meeting at the end of September.

Shelia described the material section-by-section. Not all information has been incorporated yet. Policies and programs are needed to ensure research translation does occur.

Codes will link to an appendix where there is a recommendation. Codes can also be used for scanning for finding information.

Policies are divided into eight categories: hazard testing, monitoring, risk assessment, research process, priority setting and process, etc. (see draft chapter). Shelia asked whether the Subcommittee should also include screening modalities as a section? It was unclear whether or not there would be enough space in the report. There are many examples, so some may need to go into appendices. Not sure if the State of the Science Subcommittee will be covering this topic, especially in relation to radiation exposure. For example, how do we test for radiation exposure? Radiologists carry a dosimeter, but patients do not currently carry any information with them about radiation exposure along the lines of an immunization card. Based on discussion, Shelia will cut the information on screening based on discussion and will move the radiation information to the section on chemical exposures.

One example of a case study for the precautionary principle was discussed – there may be other examples beyond the Camp LeJeune example.

Jeanne encouraged stories to be developed. The group expressed interest. A few have been discussed already. Others?

- When something has an impact on the medical community – things that are sitting out there without a coordinated communication strategy.

First area mentioned was testing – overall there is a lack of testing, need to consider mixtures, etc.

Shelia asked if any major themes were missed. The Breast Cancer Fund recommended that we include biomonitoring data that tells us where exposures might be high or high volume production chemicals.

With regard to biological biomonitoring, Shelia said that improvements are needed to expand coverage and representation from subgroups of the population. You have to measure something to change something.

Karen – looking at lead, would that be something that we might want to cite? Jeanne added that biomonitoring of lead levels which demonstrated that lead abatement programs are a seminal example of success. States to do biomonitoring. May get more into how we fund the research process and what gets biomonitored? NHANES does not provide any geographical or occupational data unless you work with the state to do it. We need to incorporate into states and locals. Don't know if this is part of CDC's Health Tracking. Health Tracking is in funding jeopardy. This group has not talked about health tracking. <http://www.cdc.gov/nceh/tracking/>

How should biomonitoring be considered in terms of the full life course?

In terms of risk assessment, multiple exposures need to be considered, along with time and age of “windows of susceptibility” and models based on animal research, etc.

The group briefly discussed TSCA reform. A significant number of chemicals are not covered by TSCA. If TSCA reform happens, it will have an impact on many agencies, but it will be fragmented. For example, Consumer Product Safety Commission, FDA is responsible for pharmaceuticals, safety of the food supply, personal care products and EPA and FDA for pesticides. Many of these products contain chemicals which could affect breast cancer risk.

Jeanne asked how we could tie in environmental justice and vulnerable populations? Shelia responded that there are gaps in groups that are sampled.

No research process and priorities are included yet in the draft policy chapter. For the time being, Jeanne recommended including bullets that can serve as questions.

Next section: community participation. Need to expand here. There are good benefits and challenges. From a policy point of view, need sharing, compensation, etc. Information included from the *National Conversation on Public Health and Chemical Exposures Report*. Liam suggested RTDPI Subcommittee could highlight advocates strength and abilities in the area of communicating with policy-makers at all levels for the purpose of informing and educating. “Science-based with a human face.”

In terms of definitions, what do we mean by “stakeholder”? We need to arrive at consistent language and definitions. Maybe look at the definitions that different agencies use? Karen recommended that we do not put definitions in the main text since we are limited in space; maybe definitions could be included as a sidebar? Connie volunteered to go through the text and identify consistencies and inconsistencies. Beverly thought this will have to be done at some point since the RTFPI may use the same word in different contexts and we have to be very clear in terms of what we are talking about.

There is a quote from the President’s Cancer Panel report about the current regulatory state being fragmented and industry interference. They also cover green chemistry, etc. and expanded use of the precautionary principle.

The RTDPI members have questions about the “standard man” used for making regulations and will pose them to the Research Process Subcommittee.

Melissa commented that in terms of interagency collaboration, bureaucracy can be frustrating, but it does serve a purpose in terms of making sure information is coordinated before it is released publicly. She will send some suggested edits to draft report language.

RTDPI members were asked to think about the key points they would like made during the presentation at the upcoming in-person meeting related to their respective sections. Connie is available to help develop PowerPoint slides (if needed), but she will need the information by the end of this week. Otherwise, RTDPI members can volunteer to take responsibility to create their own PowerPoint slides. If copies of the slides do not need to be printed prior to the meeting, they can be sent to Jenny as late as Sunday evening (September 25). If printed copies are needed, please send to Jenny by September 22<sup>nd</sup>. If everyone is confident of the direction the RTDPI teams are moving in, we can waive the need to share the information with the entire RTDPI Subcommittee for review before the in-person meeting. Each presentation will last 7-10 minutes. Jeanne will resend the timeline after the call. Shelia and Connie will work on the policy slides.

### *Communication and Dissemination Update*

This section builds on the Research Translation team report. Ysabel will ask Connie to forward a rough outline to the RTDPI members. Communication is different than dissemination and regardless of whether we are referring to scientists within agencies talking to each other or insisting they need to communicate with the public, it requires clarifying the following questions: with whom do you want to communicate with?, by whom?, and to whom? We also need to consider cultural and linguistic abilities of different stakeholders and opportunities. Ysabel is looking for examples of models and examples of missed opportunities.

Liam mentioned a researcher in Texas, John Sullivan, who really understands communication. Jeanne mentioned Liam previously provided some resources but she is hoping Liam can contribute some more information for this section in terms of community participation and strategies.

An example of a “missed opportunity” from Jeanne was the BPA study that was released yesterday that indicates BPA can interfere with tamoxifen. There is no evidence that the researchers talked with their funding agencies, advocates, etc., so there was a “missed opportunity” in terms of developing a communications strategy prior to the release of the study results.

Dissemination starts with funding and continues with communication strategists being involved in the process. Currently, it is not built into the research process or interagency communications. The RTDPI Subcommittee should mention this to the Research Process Subcommittee for consideration.

How can we describe a model that is not infused with Community-Based Participatory Research (CBPR), such as a lot of epidemiology research or animal studies? Could an individual case study or campaign serve as a model? Connie will work on developing a list of models for other types of research, interagency communication networks, etc. There are some strong models in other areas.

At the CDC, over the past few months, there have been some massive literature reviews on communication for specific cancers and there may be some information that could be gleaned from this work. Melissa will try to obtain more information on this for the RTDPI members. There is a meeting today at the CDC regarding communication strategies and modalities for breast cancer in young women because the CDC has been mandated to do a campaign targeting young women with a message about breast cancer. (This is related to Congresswoman Debbie Wasserman Schultz's breast cancer awareness bill targeting young women, which is of interest, but Jeanne doesn't think there is anything in it about breast cancer and the environment.)

Ysabel requested individual feedback be provided by the Subcommittee after the call.

Jeanne mentioned Karen has often brought up the advocates' lack of an equity position in the research process in general, and it is often an ad hoc or under-resourced position. Liam commented that this is evolving and it might be good to highlight some of the changes. Jeanne felt strategies are often under-developed because this is often left to the last minute and that is when advocates are asked to help get various messages out. Karen provided some positive examples: PIP, PEPH, and maybe PIR? Also the *National Conversation*.

Jeanne asked what the process is to evaluate the impact of communication strategies, e.g. how do you know you have effectively gotten information out and that it has been useful?

Melissa mentioned most of the work she is aware of has been done in tobacco.

Liam mentioned the PEPH metrics manual. In particular, there is a chapter on development of materials. The manual is being finalized this month. See draft manual at <http://www.niehs.nih.gov/research/supported/programs/peph/metrics/index.cfm>.

Ronda will follow-up with Ysabel and Connie to provide some examples of health communications message strategies and also work with Ysabel on presentation for upcoming in-person meeting.

### ***Research Translation Update***

Beverly said one of the most difficult issues has been distinguishing and defining "research translation" versus "translational research." Ronda agrees with the definitions but said she interpreted the emphasis of the draft chapter (based on how it was written) to be on translational research. Beverly clarified that the intention was to focus on research translation. Connie asked the Subcommittee members if they could provide any examples of translational research to help clarify for her where she has been getting off topic. If keep information on translational research, maybe add some additional distinctions? Jeanne recommended the addition of some graphics and text that help to clarify the continuum of translational research to research translation. Ysabel thought "research translation" includes aspects such as cultural and linguistic issues. Karen commented that the current draft is too focused on an academic perspective. Shelia suggested some of this could potentially be moved to an appendix. Team asked to consider what the most important themes were to highlight for research translation.

Beverly and Connie also worked independently on the matrix of ideal programs and she would like the RTDPI members to review the merged version. Connie added that she and Beverly both got pretty descriptive and was wondering if the Subcommittee wants to excerpt some core components and list them? Beverly wanted confirmation that this was the direction the Subcommittee overall thought they should head in.

For the section containing recommendations, all RTDPI members were asked to review the current draft and send comments to Connie. Beverly wanted to specifically discuss wording used for first recommendation. Karen likes the idea presented in the first recommendation but doesn't like the specific words used to convey the idea. Liam asked what is unique about the recommendation for community residents? Sounds a lot like definition of CBPR.

### ***IBCERCC Meeting in September at NIEHS***

Each Subcommittee is at a different stage of report development so draft chapters from each will not be shared prior to the meeting later this month.

The RTPDI Subcommittee needs to develop a PowerPoint presentation for the morning of Day 1. Each team should discuss and identify a presenter. Jeanne asked that those not presenting during the in-person meeting actively take notes regarding IBCERCC members' reactions to the RTDPI presentation since there will not be minutes immediately available.

The IBCERCC report format will be discussed. Take a look at the NCI Bypass Budget document as a possible report format. If there are other report formats that you would like to recommend for consideration, please bring copies to the in-person meeting and/or share web links.

Unresolved issues include:

- Report length
  - Michele Forman feels strongly that the report should have about 75 pages with appendices, although there are some other opinions about this.
- Recommendations
  - Will the recommendations be specific to each section or will they all be pulled out of sections and be listed together in the full report? Will they also be included in the Executive Summary?
  - Will recommendations be “paradigm-changing”?
- Key issues/themes to be woven throughout the report?

### **Action Items, assignments, and due dates:**

- Connie needs all requests for help with PowerPoint slides by September 20<sup>th</sup>. If can be sent earlier, that's even better!
- For anything to be printed for meeting: send revisions/final draft to Jenny by September 22<sup>nd</sup>.

- Connie to review RTDPI draft chapters for consistency of definitions/terminology used throughout. Connie will also develop list of communication models/strategies for research other than CBPR.
- Melissa to send any helpful info generated from recent CDC literature review on communication related to various cancers.
- All should review:
  - Ysabel’s draft communications and dissemination section
  - Research translation matrix and recommendations. Examples of translational research requested to help better distinguish from “research translation.”
  - [NCI Bypass Budget](#) as possible report format (including side stories). If can think of other potential report formats for consideration, please email links to RTDPI members or bring copies to the September meeting in North Carolina.

**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)