

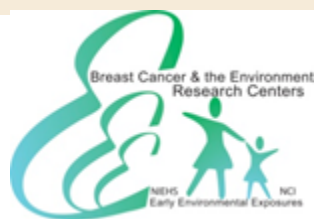


**CYGNUS CORPORATION, INC.**

**National Institute of Environmental Health Sciences (NIEHS)  
and National Cancer Institute (NCI)**

**Breast Cancer and the Environment Research Program  
(BCERP) Needs Assessment Study**

**EO Reference Number: 10-1003 NIEHS**



# **Final Report**

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Interpretation and recommendations expressed in this report are the sole responsibility of the Cygnus research team and do not necessarily represent the official views and policies of NIEHS and NCI or NIH.

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## **EXECUTIVE SUMMARY**

### **BACKGROUND**

To address the complex problem of how environmental exposures and personal susceptibility factors influence breast cancer risk, the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI) co-funded the Breast Cancer and the Environment Research Program (BCERP) in 2003. The aim of the BCERP is to study environmental exposures that may predispose a woman to breast cancer throughout her life, with a focus on specific periods of time referred to as “windows of susceptibility” when the developing breast may be more vulnerable to environmental exposures.

The program awarded grants to four institutions to establish the Breast Cancer and the Environment Research Centers (BCERCs) over an initial seven-year period. All the BCERCs worked in partnership with advocacy groups to add insight and experience to the research effort, leverage their expertise in outreach activities, and translate research results into outreach materials to improve understanding of how environmental exposures influence breast cancer risk. The BCERP was extended for another five years through new funding opportunities.

The current report presents the findings of the BCERP Needs Assessment Study funded by the NIH Evaluation Set-Aside Program. The primary objective of the study focuses on BCERP research translation and dissemination activities during the initial phase of the program. The aims of the project are to determine if translational materials developed under the BCERP are sufficient “as is,” should be modified, or if new materials are needed to effectively communicate key BCERP messages, and to identify appropriate and effective media formats for each identified target audiences. The study intends to provide NIEHS and NCI with a prioritized list of target audiences as well as their information needs, and metrics for evaluating the success of the program.

### **METHODOLOGY**

The BCERP Needs Assessment Study consists of two inter-related components: a comprehensive review of BCERP published literature from 2003 to 2010, and a structured survey of key informants. This report presents findings from the key informant interviews. Results from reviewing the BCERP published literature are contained in a separate document.

The key informant survey contains five distinct groups of individuals: (1) BCERP researchers, COTC members, and Breast Cancer and the Environment Working Group (BCEWG) scientists; (2) advocates from BCERP and BCEWG; (3) volunteers from NCI Consumer Advocates in Research and Related Activities (CARRA); (4) NIH staff who are familiar with BCERP activities; and (5) other NIH staff with expertise in communication.

Separate versions of survey questions were developed for each of the five groups of respondents. They contained (a) core questions to which all participants were asked to respond, and (b) other questions that applied to certain groups of respondents.

With the exception of the CARRA volunteers, the project’s COTR and project co-lead provided the names of potential participants for the key informant interviews. Altogether, 33 telephone

interviews were completed for the study, with an average length of interviews between 59 to 91 minutes among the five survey groups.

## **KEY STUDY FINDINGS**

The key findings of the key informant surveys of the BCERP Needs Assessment Study are summarized in the following topic areas.

### ***Knowledge of Environmental Exposures and Breast Cancer Risk***

- About two-thirds of the BCERP and BCEWG advocates and almost all of the NIH staff reported being either moderately or very familiar with the topics of environmental exposures and cancer risk, especially breast cancer risk, while all of the CARRA respondents and three out of four NIH staff reported being quite knowledgeable about risk communication.
- In seeking information pertaining to environmental influences on cancer and breast cancer risk, the more frequently mentioned sources are: (a) NIH Web sites: NCI and NLM; (b) advocacy organizations: the Breast Cancer Fund and the Silent Spring Institute Web sites; and (c) other Internet sources: WebMD site and the Google search engine.
- Regarding the primary sources for information about environmental influences on cancer and breast cancer risk designed specifically for lay audiences, the resulting responses were similar to those noted above. However, the NIH staff thought most of the information was uneven and might not be current, while the advocate respondents thought the majority of such information was very useful and effective for their needs.

### ***Basic Concepts and Communications for Target Audiences***

#### ***The General Public***

- Most of the survey respondents included in their list of basic concepts that should be understood by the general public (including parents, young children, and care givers): (a) associations between chemical exposures and early menarche and increased breast cancer risk, and (b) windows of susceptibility.
- The preferred communication formats include posting information materials on the Web site, providing printed materials, and channeling press releases and public services announcements through media organizations.
- The majority of the researchers and advocates believed quite a bit of material has already been developed and disseminated to the public. The NIH staff also thought such materials were either widely or somewhat available.

#### ***Health Care Providers***

- The survey groups identified the following basic concepts that health care providers should understand: (a) windows of susceptibility, (b) early puberty and potential consequences related to breast cancer risk, (c) chemical and environmental exposures as a risk factor, and (d) radiation from medical screening as a risk factor.
- The preferred communication formats for health care providers were: (a) continuing medical education, (b) patient education materials, and (c) online learning resources.
- More than half of the BCERP and BCEWG scientists thought that some relevant communication materials for health care providers existed already; however, the majority of advocates and NIH staff did not think so.



### Policy Makers

- The common basic concepts identified by the survey respondents for policy makers to understand about environmental influences on breast cancer risk included: (a) potential risks from environmental exposures and their association with breast cancer, and (b) the presence of chemicals in household products and breast cancer risk. Furthermore, the researchers and scientists added awareness of the precautionary principle to the list of basic concepts for policy makers; the advocates added the concepts about awareness of existing state legislation related to reducing cancer risks and knowledge of special population subgroups who are more susceptible to breast cancer; and the NIH staff included concepts on the low-dose effects of endocrine disruptors and the intergenerational nature of breast cancer.
- The preferred communication formats for policy makers included: (a) presentations and testimonials, (b) face-to-face meetings, and (c) research briefs.
- Less than half of the respondents from the different survey groups thought such materials were available.

### Media Organizations

- Respondents from the various survey groups identified different concepts for media organizations to understand. The BCERP and BCEWG scientists said media organizations should be aware of the same basic concepts as the general public; the advocates focused on the concepts of windows of susceptibility, exposures to toxic substance, and early puberty; and the NIH staff identified the timing of environmental exposures as well as intergenerational effects of exposures and gene-environment interactions.
- The preferred communications formats for media organizations were mainly (a) press releases and press conferences, (b) educational campaigns, and (c) online resources. The advocates added one-on-one meeting between researchers and the media, and the NIH staff mentioned the need to offer training for science writers and journalists, and the use of media consultants to guide researchers in their communication efforts with the media.
- Finally, more than half of the respondents from the various survey groups believed that communication materials that address the concepts identified already exist for media organizations.

## ***Government Information on Environmental Influences and Breast Cancer Risk***

- All of the NIH staff responded that they were aware of existing government sources of information specifically designed for lay audiences related to environmental influences on breast cancer risk. NCI was the most frequently mentioned source, followed by NIEHS. Almost half of the respondents stated that the existing content was quite current.
- Only a small number of NIH staff thought the existing information was moderately effective as risk communication tools.
- The main suggestions for improving existing government sources of information targeting lay audiences included: (a) make the information widely accessible, and preferably through one central site; (b) customize the information to a fifth grade reading level; (c) provide up-to-date information and the latest research findings; and (d) make the Web site visually engaging.
- In terms of key audiences for government information about the role of the environment on breast cancer risk, the top priority was the general public, followed by policy makers, women with breast cancer, and advocacy organizations and scientists.

## ***Development and Usage of BCERP Information Materials***

- All but one of the BCERP researchers, COTC members, and BCEWG scientists had been involved in the translation of BCERP research findings to materials for the lay public.
- The majority of the advocate respondents described their experience with the development of BCERP outreach materials to be either positive or very positive.
- All of the BCERP and BCEWG advocates had used some of the BCERP outreach materials mainly for educational purpose. Most of them found such materials to be very useful. However, two advocates felt the outreach materials could be improved, and despite efforts to centrally maintain copies of the materials, not all sites have submitted copies of their materials for use by all.

### ***Research Translation and Dissemination***

- Most of the survey respondents identified the following criteria for determining if a research finding is ready for translation and dissemination: rigor in study design, validity of data, reproducibility, and publication in peer-reviewed journals.
- The key behaviors identified that demonstrate effective research translation and dissemination are: (a) the target audience seeks and retains accurate information, (b) changes in consumer behavior, (c) increased number of public campaigns and advocacy activities, and (d) increased press coverage of research findings.
- In terms of the structure of a research translation and dissemination program, almost all respondents were in agreement with the need for a public-private partnership, and it should be structured around a multidisciplinary team with individuals representing scientists, health care providers, advocates, and community organizations. Also, they should work collaboratively and develop mutual understanding.

### ***Status of BCERP Research Translation***

- The NIH staff suggested that key messages related to BCERP research findings focus on two themes: (a) how environmental exposures affect breast cancer risk, and (b) steps to prevent breast cancer.
- A majority of the survey respondents had no major concerns about messages that had been developed from BCERP research findings to date.
- Respondents from advocates and the NIH staff noted that studies on early puberty and on chemicals are the key BCERP research findings that had been translated already.
- In terms of research findings ready for translation, but not yet translated, the researchers and scientists pointed to studies on early puberty and results of the epidemiological study, and the advocates identified the studies on risk associated with bisphenol A (BPA), toxicological risks of flame-retardant agents, and studies on bio-monitoring. However, the NIH staff involved in BCERP activities said all findings ready for translation had already been translated.
- Finally, when asked about the other BCERP research findings not yet ready for translation, most of the respondents said no further key research findings were ready for translation.

### ***Evaluation the Effectiveness of BCERP Information Materials***

- The BCERP researchers, COTC members, and the BCEWG scientists recommended applying pre-test and post-test methods to evaluate the impact and effectiveness of the information materials.

- The advocate respondents suggested the key evaluation metrics for measuring BCERP information materials should include surveys or focus groups to assess the target audiences' knowledge and understanding of the materials.
- To define the usefulness and effectiveness of the BCERP information materials, the advocate respondents emphasized the importance of improving people's health and changing behavior.

## **OBSERVATIONS AND RECOMMENDATIONS**

The project team received extraordinary support and valuable responses from the survey participants. The study findings should be helpful to the BCERP leadership in charting future courses of actions for the program's research translation and dissemination efforts.

In addressing the study objectives, the findings demonstrated that:

- (1) *Translational materials*: there were limited number of translated materials developed under BCERP at the time of this study, and they were mainly designed for participants in various research projects. Although some advocate respondents distributed them for outreach activities, there was a need to rewrite them into plain language science-based information for the general public as well as a need for new materials to be developed for effectively communicating key BCERP messages to various target audiences.
- (2) *Communication formats*: the recommended appropriate and effective communication formats for the general public are through the Web-based information materials, pamphlets and brochures, and public service announcements through TV, radio, and magazines. The communication formats for the health care providers should focus on patient education materials, continuing medical education, and online learning resources. For the policy makers, the effective communication formats include face-to-face meetings, presentations and testimonials, and research briefs. Finally, for the media organizations, the effective communication formats are press releases and press conferences, educational campaigns, and online resources.
- (3) *Information needs*: among the various target audiences, the primary information needs of the general public are the association between chemical exposures and early menarche and increased breast cancer risk, and the windows of susceptibility. Health care providers need the information about the windows of susceptibility, early puberty and potential consequences related to breast cancer risk, chemical and environmental exposures, and radiation from medical screening. Among the policy makers, the priority information list includes potential risks from environmental exposures and their association with breast cancer, presence of chemicals in household products, and awareness of the precautionary principle. Finally, the information needs of media organizations are association with chemical exposures and early menarche and increased breast cancer risk and windows of susceptibility.
- (4) *Evaluation metrics*: there are two primary sets of metrics for evaluating the success of the BCERP program. The first set focuses on measuring the target audiences' level of awareness, knowledge, understanding, and adoption of the BCERP messages through conducting pre- and post-surveys and/or focus groups. The second set focuses on an evaluation of the impact and extent of information dissemination through an analysis of the BCERP Web site traffic by analyzing the monthly statistics of the number of hits, unique visitors, median time per visit, top five pages views, and other relevant indicators.

However, there are a few issues raised by a number of respondents that should be taken into consideration by the BCERP leadership. These issues include:

- There is a lack of clear definitions for “research translation” and “key messages.”
- Existing tension between the belief in the precautionary principle and the desire to delay research translation and dissemination activities until a significant body of scientific evidence has accumulated has limited BCERP outreach efforts.
- There is a need to translate and disseminate published research findings even if there are no identified actionable items from the research studies.
- There is a perception among the advocates that most scientists do not like to work in a transdisciplinary framework and do not always respect the advocates on the team.

Finally, recommendations for consideration during the next phase of the BCERP initiative include the following:

- (1) Develop and finalize a comprehensive research translation and dissemination plan to facilitate the translation of the research findings into practice.
- (2) Integrate the risk communication approach into the social marketing process of disseminating the key research findings and establish guidelines for key message development and testing in the field.
- (3) Develop science-based communication guidelines about environmental influences on breast cancer risk for the various target audiences.
- (4) Design education programs for the target audiences about how to reduce environmental exposures that may affect breast cancer risk.
- (5) Develop a social marketing plan for branding the BCERP and marketing its resources to the desired target audiences.
- (6) Promote collaboration among advocates and scientists in the BCERP through establishment of collaborative grants to develop and implement science-based dissemination programs in the community and assess their impact and effectiveness through rigorous evaluation designs.

## CHAPTER 1: INTRODUCTION

### 1.1 The Breast Cancer and the Environment Research Program

To address the complex problem of how environmental exposures and personal susceptibility factors influence breast cancer risk, the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI) co-funded the Breast Cancer and the Environment Research Program (BCERP) in 2003. The aim of BCERP is to study environmental exposures that may predispose a woman to breast cancer throughout her life, with a focus on specific periods of time referred to as “windows of susceptibility” when the developing breast may be more vulnerable to environmental exposures.

The goals of the initial phase of BCERP are threefold:

- (1) Compare the molecular changes that occur in normal breast development across the lifespan to changes that occur when environmental exposures are introduced.
- (2) Conduct epidemiological studies on the timing of female pubertal events, including the onset of breast development and age at menarche, as well as environmental and genetic factors that may affect pubertal maturation.
- (3) Integrate scientific information on the development of the mammary gland and exposure-induced changes to construct public health messages for young girls and women who may be at increased risk for breast cancer.

NIEHS and NCI awarded grants to four institutions to establish the Breast Cancer and the Environment Research Centers (BCERCs) over an initial seven-year period in 2003; they were: University of California, San Francisco, University of Cincinnati, Fox Chase Cancer Center, and Michigan State University. All of the BCERCs worked in partnership with advocacy groups to add insight and experience to the research effort, leverage their expertise in outreach activities, and translate research results into outreach materials to improve understanding of the influence of environmental exposures on breast cancer risk. The Program included an advisory group, the Breast Cancer and the Environment Working Group (BCEWG), comprised of both scientists and advocates, to provide advice to the NIEHS Director on the progress of the BCERP. The BCERP was extended for another five years (2010 to 2014) through new funding opportunities.

### 1.2 Objectives of the Study

This report presents the findings of the BCERP Needs Assessment Study funded by the NIH Evaluation Set-Aside Program under Contract No. HHSN263200900305B. The primary objective of the study focuses on BCERP research translation and dissemination activities during the initial phase of the program. The aims of this study are to determine if translational materials developed under the BCERP are sufficient “as is,” should be modified, or if new materials are needed to effectively communicate key BCERP messages, and to identify appropriate and effective media formats for each identified target audience. The study intends to provide NIEHS and NCI with a prioritized list of target audiences as well as their information needs, and metrics for evaluating the success of the program.

## CHAPTER 2: METHODOLOGY

The BCERP Needs Assessment Study consists of two interrelated components: a comprehensive review of BCERP published literature and a structured survey of key informants.<sup>1</sup> The details of the data sources and survey designs are described below.

### 2.1 Review of BCERP Published Literature

The first component of the Needs Assessment Study was to conduct a comprehensive review of BCERP original research articles published in scientific journals from 2003 to 2010, individual BCERP annual progress reports provided by the Contract Officer Technical Representative (COTR), and other related outreach materials available through the BCERP Web site (<http://www.bcerc.org/home.htm>). Altogether, the review included articles of scientific research (60), epidemiological studies (14), communication research (7), editorials (2), NIEHS news briefs (5), factsheets (7), brochures (2), newsletters (9), and miscellaneous COTC publications (3). The list of BCERP published articles from 2003 to 2010 is provided in Appendix A.

In addition, a “cursory” scan of a selected group of Web sites from Government and advocacy organizations (see Appendix B) was conducted to ascertain existing key messages about environment influences on breast cancer risk.

The primary purpose of the literature review and analysis was to assess the following evaluation questions:

- What are the key existing messages about environmental influences on breast cancer risk from the government, advocates, media organizations, etc.?
- What are the key BCERP-related research findings that have already been translated to key messages? What are the target audiences?
- Are the existing messages about environmental influences on breast cancer from the BCERP, advocates, and the government consistent? If not, what are the key differences?
- Are there key BCERP research findings that have not yet been translated, but are ready for translation? If so, what are they? Who are the target audiences for these messages?
- Which key BCERP research findings are not yet ready for translation and why?
- How should a BCERP research translation and dissemination program be structured and implemented? Who needs to be involved in the BCERP research translation and dissemination program and what would be their roles?
- What key behaviors will demonstrate that the research translation and dissemination activities have been effective?

The literature review and discussion is presented in a separate report titled, *Review of Breast Cancer and the Environment Research Program Published Literature from 2003 to 2010: A Summary Report*.

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<sup>1</sup> The key informant method is a qualitative data collection technique. The researcher conducts in-depth interviews, either by telephone or face-to-face, with purposely selected individuals who are leaders and professionals and either possess specialized knowledge and expertise, have been involved in the subject matter under study, or can provide insight on the nature of problems and offer recommendations for solutions. See Marshall MN, The key informant technique, *Family Practice*, 1996, 13(1): 92-97; and USAID Center for Development and Information Evaluation, *Conducting Key Informant Interviews*, 1996.

## 2.2 Key Informant Interviews

The key informant survey, using a structured interview approach, was applied to the data collection component of the Needs Assessment Study. Five distinctive groups of individuals were invited to participate in the telephone interviews:

- BCERP researchers, COTC members, and BCEWG scientists;
- Advocates from BCERP and BCEWG;
- Volunteers from NCI's Consumer Advocates in Research and Related Activities (CARRA)<sup>2</sup> who were not involved with BCERP activities;
- NIH staff from NIEHS and NCI who were involved with BCERP activities; and
- Other NIH staff from NIEHS and NCI with expertise in various communications areas who had varying degrees of familiarity with BCERP activities.

Separate versions of survey questions were developed for each of the five groups of respondents. They contained (a) core questions to which all participants were asked to respond, and (b) other questions that applied to certain groups of respondents. The matrix of survey questions and respondent groups is presented in Table 1 below. All five sets of survey questionnaires are provided in Appendices C to G of this report.

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<sup>2</sup> CARRA began in 2001 and is a model for consumer involvement in research activities. The program was created to integrate the perspective of people affected by cancer into NCI's programs and activities.



**Table 1:  
Matrix of Survey Questions and Survey Group**

Topic	BCERP	Advocates		NIH Staff	
	Researcher, COTC & BCEWG	BCERP & BCEWG	CARRA	Involved with BCERP	Other
<i>Core Questions</i>					
What basic concepts about environmental exposures and cancer risk do target audiences (public, health care providers, policy makers, and media) need to understand?	Yes	Yes	Yes	Yes	Yes
Do materials addressing these concepts already exist?	Yes	Yes	Yes	Yes	Yes
What are the most effective formats for communication materials targeting these audiences?	Yes	Yes	Yes	Yes	Yes
What strategies/goals/guidelines are most likely to prepare target audiences to make informed decisions related to their environment and health (or to help others make these types of decisions)?	Yes	Yes	Yes	Yes	Yes
How should a BCERP research translation and dissemination program be structured and implemented?	Yes	Yes	Yes	Yes	Yes
What are your criteria for determining if a research finding is ready to be translated for lay audiences and disseminated?	Yes	Yes	Yes	Yes	Yes
<i>Other Questions</i>					
Familiarity with topic of environmental exposures and cancer risk?	DNA	Yes	Yes	Yes	Yes
Awareness prior to interview of BCERP needs assessment study?	DNA	DNA	Yes	DNA	Yes
Have you previously used BCERP outreach materials, and if so, with whom, and how useful have they been?	DNA	Yes	Yes	DNA	DNA
What resources do you use for information about environmental influences on cancer risk (especially breast cancer)?	DNA	Yes	Yes	DNA	Yes
Have you ever looked for information on this topic designed for lay audiences, and if so, what resources did you use and for what topics, were they effective, and are there any topics you were unable to find information on?	DNA	Yes	Yes	Yes	Yes



(Table 1: Continued)

Topic	BCERP	Advocates		NIH Staff	
	Researcher, COTC & BCEWG	BCERP & BCEWG	CARRA	Involved with BCERP	Other
Are you aware of existing government sources of information on this topic, and if so what resources did you use, were they effective, was the information current or outdated, and how could these materials be improved?	DNA	DNA	DNA	Yes	Yes
What target audiences is the government trying to reach, and which are most/least important?	DNA	DNA	DNA	Yes	Yes
How would you recommend integrating existing government messages with new messages in the future from BCERP and advocacy organizations?	DNA	DNA	DNA	Yes	Yes
What key messages should the BCERP focus on?	DNA	DNA	DNA	Yes	Yes
Length of involvement with BCERP?	DNA	Yes	NA	DNA	NA
What is most appropriate for BCERP outreach at the present time – raising awareness of potential influence of environment on cancer or trying to change specific behaviors?	Yes	DNA	DNA	DNA	DNA
Would you want scientific findings translated and disseminated even if there are no actionable steps to take and why?	Yes	DNA	Yes	DNA	DNA
What key BCERP findings have been translated and for which target audiences?	DNA	Yes	NA	Yes	DNA
Are there any key BCERP findings that have not yet been translated but that are ready, and if so, what are they, and who would the target audiences be?	Yes	Yes	NA	Yes	DNA
What key BCERP findings are not ready for translation and why?	Yes	Yes	NA	Yes	NA
Do you have concern about any of the messages that have already been developed from BCERP research findings?	Yes	Yes	DNA	DNA	DNA
Were you involved in BCERP research translation efforts, and if so, was the experience positive or negative and why?	Yes	Yes	NA	DNA	DNA
What are appropriate outcome/evaluation metrics to measure or assess effectiveness of future BCERP outreach materials? How would you define “useful or effective”?	Yes	Yes	Yes	DNA	DNA

DNA = Did not ask; NA = Not applicable.

### 2.3 Administration of Key Informant Surveys

With the exception of the CARRA advocates, the project’s COTR and project co-lead provided the names of potential participants for the key informant interviews. These purposively selected individuals were expected to provide insight on and knowledge of the subject matters under study and offer recommendations for solutions.

The project COTR first sent an e-mail invitation and a list of anticipated survey questions to each potential study participant. The project team<sup>3</sup> then contacted the potential participants and scheduled telephone interviews. The COTR contacted more participants than were actually interviewed. Although the COTR and project co-lead provided names of participants, they were blinded to which among the BCERP and BCEWG members were actually engaged by the project team.

To broaden the participation of advocates, the COTR also contacted the NCI’s Office of Advocacy Relations (OAR) to determine if the project team could invite members of the CARRA to participate in the BCERP Needs Assessment Study. A request for volunteers to participate on the telephone survey was forwarded through OAR to appropriate CARRA members with an interest in breast cancer. The volunteers were not required to be familiar with the BCERP to participate. The study team scheduled interviews with the first three CARRA members who responded to the invitation.

Altogether, 33 interviews were completed for the BCERP needs assessment study. The number of survey respondents, average length of interviews, and period of interviews by each group of key informants are presented in Table 2 below.

**Table 2:  
Number of Completed Interviews, Average Length of Interviews, and  
Period of Interviews by Survey Group**

Key Informant Group	Number of Completed Interviews	Average Length of Interviews	Period of Interviews
<i>Non-Advocates:</i>			
BCERP researchers, COTC members, and BCEWG scientists	9	60.1 minutes	8/18/10-9/22/10
<i>Advocates:</i>			
BCERP and BCEWG	6	70.0 minutes	9/23/10-10/18/10
CARRA	3	90.7 minutes	9/23/10-10/18/10
<i>NIH Staff:</i>			
Involved with BCERP	3	71.7 minutes	10/20/10-12/3/10
Other	12	58.6 minutes	10/20/10-12/3/10
<b>Total</b>	<b>33</b>	<b>-</b>	<b>-</b>

The telephone surveys of the non-NIH staff groups were limited to nine completed interviews each to avoid the need for clearance approval for data collection from the Office of Management

<sup>3</sup> The project team of the BCERP Needs Assessment Study was led by Dr. Henry Wong and Dr. Simin S. Wong plus other technical and support staff from Cygnus Corporation, Inc.

and Budget under the *Paperwork Reduction Act of 1995* and *5 CFR 1320* that could have resulted in lengthy delays to the start of this project.

## CHAPTER 3: STUDY FINDINGS

This chapter presents key findings of the BCERP Needs Assessment Study. The analyses are qualitative in nature, and they focus on the major themes that emerged from the key informant interviews.

### 3.1 Knowledge of Environmental Exposures and Breast Cancer Risk

The project team first attempted to learn from selected respondents the extent of their knowledge about environmental exposures and breast cancer risk. They also sought to identify respondents' information sources as well as their experience with information designed for lay audiences. The main findings from the interviews are presented below.

#### *Familiarity with Environmental Exposures and Cancer Risk*

The question about familiarity with environmental exposures and cancer risk, especially breast cancer risk, and risk communication was asked of the advocates and the NIH staff. The same question was not posed to the BCERP researchers, COTC members, and BCEWG scientific members because it was assumed they already had familiarity with such topics.

The results showed that two-thirds of the BCERP and BCEWG advocate respondents and almost all of the NIH staff reported being either moderately or very familiar with the topics of environmental exposures and cancer risk, especially breast cancer risk, while all of the CARRA respondents and three out of four NIH staff reported being quite knowledgeable about risk communication (see Table 3 below).

**Table 3:  
Familiarity with Environmental Exposures and Cancer Risk and  
Risk Communications by Survey Group**

<b>Number of respondents who were moderate or very familiar with:</b>	<b>BCERP and BCEWG Advocates (n=6)</b>	<b>CARRA Advocates (n=3)</b>	<b>NIH Staff Familiar with BCERP (n=3)</b>	<b>Other NIH Staff (n=12)</b>
Environmental exposures and cancer risk	4	1	3	11
Environmental exposures and breast cancer risk	4	1	3	11
Risk communication	2	3	1	10

#### *Primary Sources of Information*

The two advocacy groups were asked to identify where they found information pertaining to environmental influences on cancer risk, especially breast cancer. Overall, the more frequently mentioned sources are grouped as follows:

- NIH Web sites: the majority of the BCERP and BCEWG advocate respondents (four out of six) used the NCI Web site as their primary source of information about environmental influences on cancer risks. The second most frequently mentioned site was PubMed, a service of the National Library of Medicine (NLM).

- Advocacy organizations: the Breast Cancer Fund and the Silent Spring Institute Web sites were mentioned multiple times by BCERP and BCEWG advocates.
- Other Internet sources: The WebMD site and the Google search engine were two frequently mentioned Internet resources that the advocates utilized when looking for information.

***Experience with Information Designed for Lay Audiences***

The project team explored the respondents’ personal experiences with information designed for lay audiences. All of the advocate groups (BCERP, BCEWG, and CARRA) and NIH staff were asked whether they had looked for information about environmental influences on cancer risk, especially breast cancer, designed specifically for lay audiences; what were the primary sources of such information; what were the topics they looked for; how did they use the information; and how effective the information was in meeting their needs “as is.” As shown in Table 4 below, the resulting responses were quite similar between these two groups with the exception of the assessment of the effectiveness of the information in meeting their needs.

**Table 4:  
Knowledge of Communication Materials Developed for Lay Audiences  
by Advocates and NIH Staff\***

	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=15)</b>
<b>Number of respondents who ever looked for information for lay audiences</b>	8	10
<b>Frequently mentioned primary sources of information:</b>		
<i>Government Web sites:</i>	•NCI and NIEHS Web sites	•NCI Web site
<i>Advocacy organization Web sites:</i>	•Breast Cancer Fund •Silent Spring Institute	•American Cancer Society •Silent Spring Institute
<i>Other sources:</i>	•BCERP site	• No other sources mentioned
<b>Specific topics searched</b>	•Breast cancer and mammography •Chemicals and cancer risk	•Chemicals and cancer risk •Medical treatment such as hormone replacement therapy •Consumer products
<b>Use of information</b>	•Prepare outreach materials •Prepare presentations	•Prepare presentations •Respond to public inquiries •Develop information materials
<b>Effectiveness of these sources in meeting the information needs</b>	•Information was very useful and effective for their needs (5)	•Information was uneven and might not be current (6)

\*All items are listed in order from more to less frequently mentioned by survey respondents.

### 3.2 Basic Concepts and Communications for Target Audiences

All of the survey participants were asked to respond to the following questions related to environmental influences on breast cancer risk: (1) What are the basic concepts target audiences should understand about environmental influences on breast cancer risk? (2) What are the most effective formats for communicating these concepts to target audiences? (3) Do communication materials addressing these topics currently exist for target audiences?

#### *Basic Concepts and Effective Communication Format*

##### *The General Public*

The general public includes parents, their young children, and other care givers. The responses from three groups of survey respondents regarding suggested basic concepts, formats for communication materials, and opinions related to their availability are summarized below (see Table 5).

**Table 5:  
Basic Concepts and Communication Formats about Environmental Influences on Breast Cancer Risks for the General Public by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=12)</b>
<b>Basic concepts</b>	<ul style="list-style-type: none"> <li>•Connection between chemical exposures and early menarche and breast cancer development</li> <li>•Periods of exposures and windows of susceptibility</li> <li>•Role of exercise, diet, genetics, and obesity</li> </ul>	<ul style="list-style-type: none"> <li>•Exposures to various chemicals, personal and household products, and radiation in relation to cancer risk</li> <li>•Windows of susceptibility</li> <li>•Family history and genetics as they related to occurrence of breast cancer</li> <li>•Early puberty</li> </ul>	<ul style="list-style-type: none"> <li>•Risk associated with environmental exposures and how to reduce exposures to physical and chemical agents</li> <li>•Windows of susceptibility</li> <li>•Intergenerational nature of breast cancer</li> <li>•Interaction between the environment and genes</li> </ul>
<b>Communication formats</b>	<ul style="list-style-type: none"> <li>•Pamphlets, brochures, plastic wallet cards</li> <li>•TV messages, talk shows, magazines, billboards</li> <li>•Internet sites</li> </ul>	<ul style="list-style-type: none"> <li>•Internet and social media</li> <li>•Interactive games for children</li> <li>•Brochures, pamphlets</li> <li>•Magazines, PSAs</li> <li>•Presentations by experts at community meetings</li> </ul>	<ul style="list-style-type: none"> <li>•Internet and social media</li> <li>•PSAs<sup>4</sup> in TV and radio</li> <li>•Working through advocacy groups to channel the messages</li> </ul>
<b>Availability of communication materials</b>	<ul style="list-style-type: none"> <li>•Quite a bit of materials had been disseminated to the general public (5)</li> </ul>	<ul style="list-style-type: none"> <li>•Some materials have already developed and disseminated (6)</li> </ul>	<ul style="list-style-type: none"> <li>•Such materials were either widely or somewhat available (6)</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

<sup>4</sup> PSA: public service announcement.

**Health Care Providers**

The suggested concepts for health care providers to understand, the most effective formats for communication materials targeting this audience, and their availability are summarized in Table 6 below.

**Table 6:  
Basic Concepts and Communication Formats about Environmental Influences on Breast Cancer Risks for Health Care Providers by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=14)</b>
<b>Basic concepts</b>	<ul style="list-style-type: none"> <li>•Chemical exposures in early life</li> <li>•Puberty and age at menarche</li> <li>•Childhood obesity and breast cancer</li> <li>•Critical period of exposures and windows of susceptibility</li> <li>•Association between personal care products and breast cancer risk</li> </ul>	<ul style="list-style-type: none"> <li>•Environmental exposures as risk factor</li> <li>•Early puberty and potential consequences</li> <li>•Windows of susceptibility throughout the lifespan</li> <li>•Risk of radiation from mammography</li> </ul>	<ul style="list-style-type: none"> <li>•Provide scientific facts for patient education</li> <li>•Detect environmental exposures through screening</li> <li>•Endocrine disruptors</li> <li>•Windows of susceptibility</li> <li>•Intergenerational effects of exposures</li> <li>•Influence of life style choices related to breast cancer risk</li> </ul>
<b>Communication formats</b>	<ul style="list-style-type: none"> <li>•Continuing medical education (CME)</li> <li>•Grand rounds for pediatricians, obstetricians, and primary care physicians</li> <li>•Scientific literature</li> <li>•Tool kits for pediatricians</li> <li>•Online learning and Web-based resources</li> </ul>	<ul style="list-style-type: none"> <li>•CME, Webinars, and Web dialogues</li> <li>•Provide research findings and online videos on the Web</li> <li>•Add environmental exposures and risk factors in medical school curriculum</li> <li>•Scientific articles for patient education</li> </ul>	<ul style="list-style-type: none"> <li>•Scientific literature</li> <li>•Brochures, newsletters, tool kits, and related patient education materials</li> <li>•CME and presentations at professional society meetings</li> </ul>
<b>Availability of communication materials</b>	<ul style="list-style-type: none"> <li>•Some communication materials exist already (5)</li> </ul>	<ul style="list-style-type: none"> <li>•Communication materials for health care providers exists (1)</li> </ul>	<ul style="list-style-type: none"> <li>•Some of these materials are available (3)</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

**Policy Makers**

The suggested concepts for policy makers to understand, the most effective formats for communication materials targeting this audience, and their availability are summarized in Table 7 below.

**Table 7:  
Basic Concepts and Communication Formats about Environmental Influences on Breast Cancer Risks for Policy Makers by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=14)</b>
<b>Basic concepts</b>	<ul style="list-style-type: none"> <li>•Concepts of risk factors and environmental exposures</li> <li>•Presence of chemicals in household products and breast cancer risk</li> <li>•Awareness of the precautionary principle<sup>5</sup></li> </ul>	<ul style="list-style-type: none"> <li>•Concepts related to chemical body burden and determinants of cancer susceptibility</li> <li>•Awareness of existing legislations from other States related to reducing cancer risks</li> <li>•Knowledge of special population subgroups who are more susceptible to breast cancer</li> <li>•Distinction between preventive and curative care</li> <li>•Put precautionary principle into policies</li> </ul>	<ul style="list-style-type: none"> <li>•Potential risks associated with environmental exposures and breast cancer</li> <li>•Low-dose effects of endocrine disruptors</li> <li>•Intergenerational nature of breast cancer</li> <li>•Economic impact of environmental exposures and cancer risk to the society</li> </ul>
<b>Communication formats</b>	<ul style="list-style-type: none"> <li>•Presentations and testimonials</li> <li>•Face-to-face meetings</li> <li>•Research briefs/white papers</li> </ul>	<ul style="list-style-type: none"> <li>•Evidence-based testimonies</li> <li>•Policy papers based on peer-reviewed research findings</li> <li>•One-on-one dialogue</li> <li>•Mass e-mails</li> </ul>	<ul style="list-style-type: none"> <li>•Face-to-face briefings and presentations</li> <li>•One-page briefings/fact sheets</li> </ul>
<b>Availability of communication materials</b>	<ul style="list-style-type: none"> <li>•Such materials are available (4)</li> </ul>	<ul style="list-style-type: none"> <li>•Such materials are available (4)</li> </ul>	<ul style="list-style-type: none"> <li>•At least some of these materials are available (6)</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

<sup>5</sup>The “precautionary principle” was defined in a 1998 consensus statement as “when an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically.” See Kriebel D et al., The precautionary principle in environmental science, *Environmental Health Perspectives*, 109: 871-876.



***Media Organizations***

The suggested concepts that the media organizations should understand, the most effective formats for communication materials targeting this audience, and their availability are summarized in Table 8 below. It should be noted many respondents cautioned that the media organizations are different from the other target audiences because they tend to sensationalize research results and at times overlay preliminary findings, and members of the media organizations should focus on the facts.

**Table 8:  
Basic Concepts and Communication Formats about Environmental Influences on Breast Cancer Risks for the Media Organizations by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=12)</b>
<b>Basic concepts</b>	<ul style="list-style-type: none"> <li>•Connection between chemical exposures and early menarche and breast cancer development</li> <li>•Periods of exposures and windows of susceptibility.</li> <li>•Role of exercise, diet, genetics, and obesity</li> <li>•Focusing on prevention because a substantial portion of breast cancer could be prevented</li> </ul>	<ul style="list-style-type: none"> <li>•Windows of susceptibility</li> <li>•Exposures to toxic substance</li> <li>•Early puberty</li> <li>•Radiation and risk of mammography</li> </ul>	<ul style="list-style-type: none"> <li>•Timing of environmental exposures</li> <li>•Intergenerational effects of exposures</li> <li>•Gene-environment interactions</li> <li>•Endocrine disruptors</li> </ul>
<b>Communication formats</b>	<ul style="list-style-type: none"> <li>•Press releases based on accurate data</li> <li>•Educational campaigns</li> <li>•Web resources</li> </ul>	<ul style="list-style-type: none"> <li>•One-on-one meeting with researchers</li> <li>•Educational campaigns in collaboration with entertainers and philanthropic leaders</li> <li>•Press conference and newsletters</li> <li>•Paid advertisement</li> </ul>	<ul style="list-style-type: none"> <li>•Fact sheets tailored for press releases</li> <li>•Seminars or online training for science writers or journalists</li> <li>•Engaging media consultants to guide researchers to communicate with the media</li> <li>•Assigning scientists to talk to media organizations about study findings</li> </ul>
<b>Availability of communication materials</b>	<ul style="list-style-type: none"> <li>•Communication materials already existed for the media as evidenced by the number of press releases to date (7)</li> </ul>	<ul style="list-style-type: none"> <li>•Such materials exist (5)</li> </ul>	<ul style="list-style-type: none"> <li>•Some materials are available to media organizations (8)</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

***Raising Awareness versus Changing Specific Behaviors***

The BCERP researchers and COTC and BCEWG members were specifically asked if “raising awareness about the potential influence of the environment on cancer” or “changing specific behaviors” was more appropriate at this point in time. Six out of nine respondents said “raising awareness” was a more appropriate goal. Two respondents added that once the public are made aware of the potential influence of the environment on cancer, they would then want to know how they could reduce harmful exposures.

It should be noted that two respondents said both choices were important and could not be separated from each other, and are dependent on the research findings. One of these respondents stressed the need for building an ongoing relationship with the public and informing them on a continuous basis about the research findings.

### *Strategies to Prepare Target Audiences to Make Informed Decisions*

All the respondents were asked about strategies, goals, and guidelines that are most likely to prepare the target audiences (i.e., general public, health care providers, policy makers, and media organizations) to make informed decisions related to environmental exposures and their health. As shown in Table 9 (below), there were common suggestions for different target audiences offered by the three groups of survey respondents.

**Table 9:  
Strategies to Prepare Target Audiences to Make Informed Decisions by Survey Groups\***

<b>Target Group</b>	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG and CARRA Advocates (n=9)</b>	<b>NIH Staff (n=13)</b>
<b>General public</b>	<ul style="list-style-type: none"> <li>•Ensure the appropriate level of health literacy of the messages and materials</li> <li>•Prepare well-written outreach materials with accurate data</li> <li>•Identify the study sponsorship from the government</li> <li>•Emphasize strength of scientific evidence</li> </ul>	<ul style="list-style-type: none"> <li>•Ensure the appropriate level of health and science literacy</li> <li>•Use simple language</li> <li>•Involve the public in the research from the beginning</li> <li>•Communicate with the public through community meetings</li> <li>•Use social media channels to disseminate messages</li> </ul>	<ul style="list-style-type: none"> <li>•Provide up-to-date fact sheets about environmental exposures and breast cancer risk</li> <li>•Use multimedia formats to deliver concise messages</li> <li>•Provide decision tools to help the public understand what they could and could not do</li> <li>•Understand the level of health and science literacy of the public</li> <li>•Integrate the subject matter into science education in schools</li> </ul>
<b>Health care providers</b>	<ul style="list-style-type: none"> <li>•Develop guidelines and information sheets for clinical use</li> <li>•Develop patient education materials</li> </ul>	<ul style="list-style-type: none"> <li>•Organize education forums, training courses, and CME</li> <li>•Develop guidelines and factsheets for patients</li> <li>•Post research findings on BCERP Web site</li> </ul>	<ul style="list-style-type: none"> <li>•Provide synthesized information about environmental exposures and breast cancer risk</li> <li>•Offer CME, workshops, and online training programs</li> </ul>

(Table 9: continued)

Target Group	BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)	BCERP, BCEWG and CARRA Advocates (n=9)	NIH Staff (n=13)
<b>Policy makers</b>	<ul style="list-style-type: none"> <li>•Develop materials to show economic and political impacts</li> <li>•Prepare briefings to emphasize the cost-effectiveness of prevention</li> <li>•Provide materials for addressing their constituents</li> </ul>	<ul style="list-style-type: none"> <li>•Bring the top aides of policy makers to the meetings.</li> <li>•Deliver presentations to constituents and special interest groups.</li> </ul>	<ul style="list-style-type: none"> <li>•Make available credible resources and current scientific findings.</li> <li>•Prepare annual policy briefings.</li> <li>•Develop key messages for policy makers to pitch to the Congress.</li> </ul>
<b>Media organizations</b>	<ul style="list-style-type: none"> <li>•Establish long-lasting relationship with the media</li> <li>•Provide accurate and newsworthy research findings</li> <li>•Create media kits</li> <li>•Conduct focus groups or meetings with media organizations</li> </ul>	<ul style="list-style-type: none"> <li>•Provide newsworthy study results with accurate data when available</li> <li>•Establish partnerships with the media</li> </ul>	<ul style="list-style-type: none"> <li>•Provide tailored news releases or press kits on important findings</li> <li>•Provide links to scientific studies</li> <li>•Provide easy access to BCERP scientists</li> <li>•Provide special training for the media on the science related to environmental exposures and breast cancer risk</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

### 3.3 Government Information on Environmental Influence and Breast Cancer Risk

Respondents were asked about their awareness of governmental information on environmental influences and breast cancer risk, key audiences for governmental information, and how to integrate existing governmental messages with the messages from BCERP. The responses from the 15 NIH staff indicated that additional efforts are needed in delivering effective information and messages to the target audiences.

#### *Awareness of Government Information on Environmental Influences and Breast Cancer Risk*

All 15 NIH staff responded that they were aware of existing governmental sources of information specifically designed for lay audiences related to environmental influences on breast cancer risk. NCI was the most frequently mentioned source, identified by 12 respondents, followed by NIEHS, mentioned by eight NIH staff participating in this survey.

When respondents were asked how effective they thought the identified sources were as risk communication tools, only five of the 15 respondents indicated that the existing information was moderately effective, and two either thought the identified sources were less than moderately effective or not effective. Only one respondent described the existing sources as very useful. However, four respondents, including one of the NIH staff “involved” in the BCERP, stressed that these sources were not risk communication tools; rather, they were designed for educational or study recruitment purposes.

When asked, almost half of the NIH staff (seven of the 15) stated that the content of the existing government sources was quite current and that most information is updated on a regular basis. However, three respondents (two of whom are “involved” in the BCERP) said the materials were out of date.

Suggestions from survey respondents for improving existing government sources of information targeting lay audiences included the following:

- Make the information widely accessible, preferably through one central site;
- Modify the information whenever possible to a fifth grade reading level and develop actionable statements;<sup>6</sup>
- Provide up-to-date information and the latest research findings; and
- Make Web sites visually engaging and include more graphics.

### ***Key Audiences for Government Information about the Role of the Environment and Cancer***

When the NIH staff were asked which target audience(s) they think the government tries to reach with information related to the role of the environment and cancer, especially breast cancer, they provided the following responses:

- The general public, including family members and minority women (8);
- Policy makers, including Congress and public health agencies (7);
- Women with breast cancer, or at risk for developing breast cancer (6); and
- Advocacy organizations and research scientists (5).

The respondents were then asked to select two target audiences among those mentioned that were, in their opinion, the most important to reach. The most frequently mentioned target audiences were:

- The general public, including parents and their children, young women, less educated women, and people living in rural areas (11);
- Advocacy groups (5);
- Health care providers (4); and
- Policy makers, including regulatory agencies (4).

In addition, six respondents indicated there were no unimportant or “least important” target audiences.

### ***Integrating Existing Government Messages with New Messages from BCERP***

NIH staff provided the following recommendations for integrating existing governmental and advocacy-developed messages relevant to environmental influences on breast cancer risk with new messages developed by the BCERP over the next few years:

1. Changes in messages need to be explained: Six respondents suggested undertaking an analysis of new evidence and explaining why message changes are necessary to reduce confusion among the target audiences.
2. Processes for integrating new messages with existing messages need to be developed: Four respondents indicated the preferred approach is to establish a process for integration

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<sup>6</sup> The current BCERP outreach materials do not have any accompanying information indicating who the target audience is, the reading level of the material, etc., and there was some concern from the survey respondents that the existing materials are too complex for the general public and suggested the reading level be set around the fifth grade.

- between the BCERP and NIEHS/NCI. The new process could include the establishment of a coordinating group that would work with the BCERP grantees, NIH, and other government agencies, such as CDC, or develop a consensus process and/or an action plan to review and compare old messages against new messages before informing the target audiences.
3. Communication approaches need to be adjusted: Two respondents suggested changing the approach used to communicate the importance of new messages to help the target audiences understand the reasons behind the changes. This could be accomplished through an organized educational or media campaign to communicate new messages to the public.

### **3.4 Development and Usage of BCERP Information Materials**

The questions focused on participants' involvement in BCERP research translation activities, development of key BCERP measures, and experience with using BCERP outreach materials produced more divergent views among the survey respondents than any other set of Needs Assessment survey questions.

#### ***Involvement in the BCERP Research Translation***

The BCERP researchers, COTC members, and BCEWG scientists were asked about their involvement in the research translation efforts of the BCERP research findings.

All but one of the nine respondents from the BCERP researchers, COTC members, and BCEWG scientists had been involved in the translation of BCERP research findings to materials for the lay public. They described the experience as both positive and negative. On the positive side, the respondents indicated that they:

- appreciated the opportunity to work together as a team of research scientists, COTC members, and advocates;
- liked to receive comments and exchange ideas; and
- liked opportunities to present research findings to community advisory boards and town hall meetings.

As for the negative aspects, most of the BCERP scientists and COTC members felt that there were too many advocates around the table who were not skilled in research translation and social marketing.

#### ***Advocate Involvement in the Development of BCERP Outreach Materials***

The BCERP and BCEWG advocate members were asked about their direct involvement in the development of the BCERP outreach materials. Their participation included the development of newsletters, brochures, factsheets, and the BCERP Web site.

The respondents described their experiences with the BCERP to be either positive or very positive. However, one advocate reflected that, although the experience was positive, it was "extremely difficult" to obtain research findings from the scientists because the scientists felt that the findings were not "beyond a shadow of a doubt." This same advocate also pointed out that the precautionary principle in disease prevention was not being considered. Another BCEWG advocate member suggested that it would have been more productive to bring in the COTC members later in the program because the COTC did not have any significant roles during the early years while the scientists were focused on initiating their research studies.

### *Use of, and Satisfaction with, BCERP Outreach Materials*

All six of the BCERP and BCEWG advocate members had used some of the BCERP outreach materials, mainly for educational purposes, such as informing the public during community outreach functions and sharing the materials with other advocates and cancer patients. One of the advocate members from the BCEWG noted that she had taken what she learned from BCERP study findings and developed them into plain language, science-based information for the general public.

The three BCEWG respondents and two of the BCERP advocates found the BCERP outreach materials to be very useful. Two BCEWG respondents were very satisfied with the BCERP outreach materials; however, two BCERP advocates said that BCERP outreach materials could be improved. They added that although a great deal of information is available, the materials are scattered and are not being assembled, which would make them more useful in explaining the effects of environmental exposures and breast cancer risk to various audiences.

### **3.5 Research Translation and Dissemination**

The study participants were asked to offer their professional views and opinions about criteria for determining readiness of research findings for translation and dissemination, key behaviors that demonstrate effectiveness of research translation and dissemination, and their recommended structure of a research translation and dissemination program.

#### *Criteria for Determining Research Findings Readiness for Translation and Dissemination*

The survey respondents were asked about their criteria for determining if a research finding is ready to be translated for the public and disseminated. This was followed by questions about the translation and dissemination of messages without actionable recommendations. As shown in Table 10 below, the findings from the survey respondents are rather consistent across the groups.

**Table 10:  
Criteria for Determining Readiness for Translation and Dissemination  
of Research Findings by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n = 9)</b>	<b>BCERC, BCEWG, and CARRA Advocates (n = 9)</b>	<b>NIH Staff (n =14)</b>
<b>Criteria for readiness for translation and dissemination</b>	<ul style="list-style-type: none"> <li>•Consistency</li> <li>•Reproducibility</li> <li>•Rigor in study</li> <li>•Validity of data</li> <li>•Credibility</li> <li>•Published in peer-reviewed journals</li> <li>•Availability of clear conclusions</li> </ul>	<ul style="list-style-type: none"> <li>•Statistical significant</li> <li>•Validated by multiple studies</li> <li>•Published in peer-reviewed journals</li> </ul>	<ul style="list-style-type: none"> <li>•Replicable studies with similar results</li> <li>•Consensus agreement among researchers</li> <li>•Conducted under robust research design</li> <li>•Findings of statistical significance</li> <li>•Published in peer-reviewed journals</li> </ul>
<b>Number of respondents who said “yes” to findings translated and disseminated with no actionable item</b>	9	7	9
<b>Reasons of saying “yes”</b>	<ul style="list-style-type: none"> <li>•Inform and educate the public about the results and raise public awareness</li> <li>•Follow the precautionary principle</li> <li>•Studies publicly funded</li> </ul>	<ul style="list-style-type: none"> <li>•Inform the public about the results</li> <li>•Transparency and trust</li> <li>•Results could be actionable “tomorrow”</li> <li>•Studies were publicly funded</li> </ul>	<ul style="list-style-type: none"> <li>•Studies publicly funded</li> <li>•Public has the right to know the research findings</li> <li>•Stimulate innovative thinking and help increase understanding of unanswered research questions</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

***Key Behaviors That Demonstrate Effectiveness of Research Translation and Dissemination***

Five of the NIH staff were asked about key behaviors that would demonstrate that BCERP research translation and dissemination activities have been effective. Key behaviors mentioned included:

- “Obtain accurate information” and “retain accurate knowledge” as measured by pre-test and post-test,
- Change in consumer behavior with more consciousness of reviewing consumer product ingredients,
- Increase in public campaigns and advocacy activities to introduce legislation related to banning harmful chemicals in consumer products, and



- Increase in press coverage and public speeches about research findings related to environmental exposures and breast cancer risk.

***Structure of a Research Translation and Dissemination Program***

The survey participants were asked for recommendations for structuring and implementing a research translation and dissemination program focused on environmental influences on breast cancer risk. Overall, almost all of the survey respondents were in agreement about the need for a public-private partnership. A research translation and dissemination program should be structured around a multidisciplinary team with individuals representing scientists, health care providers, advocacy groups, and community organizations. They should work collaboratively and develop mutual understanding.

The most frequently mentioned team members and their roles can be summarized as follow (see Table 11).

**Table 11:  
Proposed Structure and Roles of a BCERP Research Translation  
and Dissemination Program**

<b>Team Member/Discipline</b>	<b>Role</b>
Research scientists	Ensure accuracy of the data and information.
Science writers	Translate complex research and make science understandable.
Communication researchers/Risk communication experts/Health educators	Assess the level of literacy of outreach and communication materials.
Public relations specialists/Journalists	Present information creatively.
Community advocates	Disseminate study messages and outreach materials.
Federal and State health officials and health policy experts	Form partnership in policy initiatives.
General public	Represent consumer perspectives.

Two additional types of concerns were raised by the study respondents:

- The advocates generally felt that most scientists do not like to work in a transdisciplinary framework and do not always respect the advocates on the team. The advocates expressed a level of unease with the scientists in the collaborative process.
- Some of the BCERP scientists and COTC members noted various problems with the BCERP research translation efforts to date, including: (a) lack of funding to support such a program; and (b) lack of consensus and coordination within individual research teams and COTC members and between the national coordination center and individual study sites.



### 3.6 Status of BCERP Research Translation

In reviewing the status of BCERP research translation efforts, the project team asked respondents to focus on the key messages of the BCERP research findings and to identify the BCERP research findings that have already been translated, those that have not been translated but are ready for translation, and those that are not ready for translation.

#### *Key Messages of the BCERP Research Findings*

NIH staff were asked what key messages BCERP should focus on. Despite a wide range of answers, the suggested messages related to the following themes:

- Environmental exposures affect breast cancer risk: Six NIH respondents focused on the impact of environmental exposures through all stages of a woman's lifespan contributing to the risk of developing breast cancer. Messages should be developed to educate target audiences about avoiding exposures to chemicals known to be risk factors in the development of breast cancer.
- Take steps to prevent breast cancer: Four NIH respondents suggested that the target audiences should know what steps they could take to reduce their risk of breast cancer and avoid environmental exposures associated with an increased risk of developing breast cancer. They also said that the public should be provided with the research findings, distinguishing between those findings that have been definitively proven and those which are preliminary findings.

#### *Concerns Related to BCERP Key Messages*

Concerns about key BCERP messages were discussed by two groups of respondents: (1) the BCERP researchers, COTC members, and BCEWG scientists; and (2) BCERP and BCEWG advocates. A majority of respondents from the first group and half from the second group said they had no concern about messages that had been developed from BCERP research findings to date. One believed the scientists had been fairly conservative in that they would not release any data until they were peer-reviewed and published.

Concerns raised about BCERP messages are summarized in Table 12 below. It is noted that the types of concerns are significantly different between the two groups of respondents.

Furthermore, scientific publications from the BCERP studies are increasing; however, at the time of this study, the BCERP COTCs posted on the Website with only a total of seven fact sheets about chemicals being studied in the research projects and BMI measurement.<sup>7</sup> The chemical fact sheets all exceeded the eighth grade reading level based on the Flesch-Kincaid readability test, which could limit their usefulness with lay audiences.

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<sup>7</sup> There are significant numbers of outreach materials produced by individual BCERCs and listed on their annual progress reports. However, they were not available to the Needs Assessment Study team for review.

**Table 12:  
Concerns about Key BCERP Messages by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP and BCEWG Advocates (n = 6)</b>
<b>Number of respondents who raised concerns</b>	4	3
<b>Types of concerns</b>	<ul style="list-style-type: none"> <li>•The factsheets are too detailed and not well-suited for the general public</li> <li>•The Web site is not visually appealing and not useful</li> <li>•Some information materials are questionable as to whether they are based on the study findings</li> <li>•Lack of coordination in the BCERP beginning when research findings are approved for publication through the determination of when ready for translation</li> </ul>	<ul style="list-style-type: none"> <li>•The messages are as strong as advocates would like to see to effect behavior change</li> <li>•The public should be guided towards the precautionary principle</li> <li>•The BCERP is not aggressive in disseminating their messages, and the messages are not in simple language for all audiences</li> <li>•Some scientists are unwilling to work within a transdisciplinary environment</li> </ul>
<b>Notable additional comments and suggestions</b>	<ul style="list-style-type: none"> <li>•A list of messages developed by BCERP to date needs to be prepared</li> <li>•No media messages should be developed unless the findings are definitive and certain</li> </ul>	<ul style="list-style-type: none"> <li>•The scientists on the environmental and genetic determinants of early puberty study have not yet revealed the research findings</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

***Key BCERP Research Findings Already Translated***

The BCERP and BCEWG advocates and the NIH staff involved in BCERP activities were asked whether key BCERP research findings had been translated already. It is noted that majority of the respondents identified the studies on early puberty as the primary research findings that have been translated (see Table 13).

**Table 13:  
Key BCERP Research Findings Already Translated by Survey Group\***

<b>BCERC and BCEWG Advocates (n = 6)</b>	<b>NIH Staff (n = 3)</b>
<ul style="list-style-type: none"> <li>•Studies on early puberty</li> <li>•Biology studies on chemicals</li> <li>•Studies on diet, obesity, and pregnancy</li> </ul>	<ul style="list-style-type: none"> <li>•Studies on early puberty</li> <li>•Studies on detection of classes of chemicals in young girls</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

***Key BCERP Research Findings Not Yet Translated but Ready for Translation***

In contrast to the findings above, three BCERP research scientists pointed out that the early puberty studies were ready but not yet translated (see Table 14). Two out of three NIH respondents said no BCERP research finding were ready for translation that had not already been translated.

**Table 14:  
Key BCERP Research Findings Not Yet Translated but Ready for Translation  
by Survey Group\***

<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP and BCEWG Advocates (n=6)</b>	<b>NIH Staff Involved in BCERP Activities (n=3)</b>
<ul style="list-style-type: none"> <li>•Studies on early puberty</li> <li>•Results of the epidemiological study</li> </ul>	<ul style="list-style-type: none"> <li>•Studies on risk associated with BPA and toxicological risks of flame-retardant agents</li> <li>•Studies on bio-monitoring</li> </ul>	<ul style="list-style-type: none"> <li>•None were ready for translation that had not already been translated</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

***Key BCERP Research Findings Not Ready for Translation***

Finally, when asked about other BCERP research findings not yet ready for translation, most of the respondents said no further key research findings were ready for translation. A number of BCERP researchers and NIH staff noted that the epidemiological studies and animal studies were still ongoing and not yet ready for translation (see Table 15).

One BCEWG scientific member firmly believed that all results should be ready for translation after being published in peer-reviewed journals, while another BCERP researcher stated that it should be up to investigators to decide if their research findings are ready for translation.

**Table 15:  
Key BCERP Research Findings Not Ready for Translation by Survey Group\***

<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP and BCEWG Advocates (n=6)</b>	<b>NIH Staff Involved in BCERP Activities (n=3)</b>
<ul style="list-style-type: none"> <li>•Epidemiological studies</li> <li>•Animal studies</li> </ul>	<ul style="list-style-type: none"> <li>•Basic science studies on low-dose ionizing radiation as an environmental stressor</li> <li>•Epidemiological studies</li> </ul>	<ul style="list-style-type: none"> <li>•Studies on association of certain chemicals in girls with early puberty</li> <li>•Studies on association of absence of biological father and early pubertal development</li> <li>•Findings from the animal studies related to environmental exposures</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

### 3.7 Evaluation of the Effectiveness of BCERP Information Materials

Respondents were asked about appropriate outcome and evaluation metrics for measuring or assessing the effectiveness of future BCERP outreach materials. Two groups of respondents, the scientists and the advocates, were asked to offer their views on this topic, including how they would define “useful” or “effective” measures. Their overall suggestions are grouped as follows (see Table 16).

**Table 16:  
Suggested Evaluation Metrics of Measuring BCERP Information Materials  
by Survey Group\***

	<b>BCERP Researchers, COTC Members, and BCEWG Scientists (n=9)</b>	<b>BCERP, BCEWG, and CARRA Advocates (n=9)</b>
<b>Evaluation metrics</b>	<ul style="list-style-type: none"> <li>•Apply pre-test and post-test methods to evaluate the impact and effectiveness of the information materials</li> <li>•Measure the saturation rates of the number of people who were sent, received, read, and adopted the messages</li> <li>•Assess the information materials in terms of accuracy, consistency, clarity, relevance, and reproducibility</li> <li>•Analyze the BCERP Web sites in terms of monthly number of visits, repeat visits, and other measures</li> </ul>	<ul style="list-style-type: none"> <li>•Conduct survey or focus groups to assess the target audiences’ knowledge and understanding of the BCERP information materials</li> <li>•Measure the amount of feedback received and/or the number of “hits” to the project Web sites</li> </ul>
<b>Defining usefulness and effectiveness</b>	(None provided)	<ul style="list-style-type: none"> <li>•The importance of improving people’s health and changing behavior</li> <li>•Information materials that are actionable with a large impact (e.g., breast cancer prevention)</li> <li>•The results showing a reduction in incidence and prevalence rates of breast cancer</li> </ul>

\*All items are listed in order from more to less frequently mentioned by survey respondents.

## CHAPTER 4: OBSERVATIONS AND RECOMMENDATIONS

### 4.1 Overall Observations

Overall, the BCERP Needs Assessment Study, initiated to guide message development and dissemination to key target audiences, has been completed. The project team received extraordinary support and valuable responses from the study participants. The study findings should aid the BCERP leadership in charting future courses of actions of the program's research translation and dissemination efforts.

The study findings demonstrated that the various groups of purposefully selected key informants possessed knowledge on the subject matter of environmental exposures and breast cancer risk, accumulated experience with information designed for lay audiences, helped the study team identify basic concepts related to environmental exposures and breast cancer risk and effective communication strategies for specific target audiences, believed messages that focus on raising awareness about potential influences of environmental exposures on breast cancer risk were appropriate, and identified strategies to prepare target audiences to make informed decisions.

The respondents also provided important insights pertaining to: (a) criteria for determining readiness of research findings for translation and dissemination; (b) key behaviors that demonstrate effectiveness of research translation and dissemination; (c) recommendations for structuring and implementing a research translation and dissemination program focused on environmental influences on breast cancer risk; and (d) suggestions about evaluation metrics for measuring the effectiveness of future BCERP outreach materials.

Specifically related to the objectives of the BCERP Needs Assessment Study, the findings demonstrated that:

- (1) *Translational materials*: there were limited number of translated materials developed under BCERP at the time of this study, and they were mainly designed for participants in various research projects. Although some advocate respondents distributed them for outreach activities, there was the need to rewrite them into plain language science-based information for the general public, as well as the need for new materials to be developed for effectively communicating key BCERP messages to various target audiences.
- (2) *Communication formats*: the recommended appropriate and effective communication formats for each target audiences are listed in Table 17 below.

**Table 17:  
Appropriate and Effective Communication Formats for Each Target Audiences**

Target Audience	Effective Communication Format
General public	<ul style="list-style-type: none"> <li>•Web-based information materials</li> <li>•Pamphlets and brochures</li> <li>•PSAs through TV, radio, and magazines</li> </ul>
Health care providers	<ul style="list-style-type: none"> <li>•Patient education materials</li> <li>•Continuing medical education</li> <li>•Online learning resources</li> </ul>
Policy makers	<ul style="list-style-type: none"> <li>•Face-to-face meetings</li> <li>•Presentations and testimonials</li> <li>•Research briefs</li> </ul>
Media organizations	<ul style="list-style-type: none"> <li>•Press releases and press conferences</li> <li>•Educational campaigns</li> <li>•Online resources</li> </ul>

(3) *Information needs*: the prioritized list of target audiences and their information needs is presented in Table 18 below.

**Table 18:  
Prioritized List of Target Audiences and Their Information Needs**

Target Audience	Information Needs
General public	<ul style="list-style-type: none"> <li>•Association between chemical exposures and early menarche and increased breast cancer risk</li> <li>•Windows of susceptibility</li> </ul>
Health care providers	<ul style="list-style-type: none"> <li>•Windows of susceptibility</li> <li>•Early puberty and potential consequences related to breast cancer risk</li> <li>•Chemical and environmental exposures</li> <li>•Radiation from medical screening</li> </ul>
Policy makers	<ul style="list-style-type: none"> <li>•Potential risks from environmental exposures and their association with breast cancer</li> <li>•Presence of chemicals in household products</li> <li>•Awareness of the precautionary principle</li> </ul>
Media organizations	<ul style="list-style-type: none"> <li>•Association between chemical exposures and early menarche and increased breast cancer risk</li> <li>•Windows of susceptibility</li> </ul>

(4) *Evaluation metrics*: there are two primary sets of metrics for evaluating the success of the BCERP program: (a) the first set focuses on the measuring the target audiences' level of awareness, knowledge, understanding, and adoption of the BCERP messages through

conducting pre- and post-surveys and/or focus groups; and (b) the second set focuses on evaluation of the impact and extent of information dissemination through the BCERP Web site traffic analysis by analyzing the monthly statistics of the number of hits, unique visitors, median time per visit, top five pages views, and other relevant indicators.

However, there are a few issues raised by a number of respondents that should be taken into consideration by the BCERP leadership:

- The lack of clear definitions of “research translation” and “key messages.” Publishing research findings in peer-reviewed scientific journals is not necessarily considered research translation nor is producing a factsheet equivalent to creating a key message.<sup>8</sup>
- The “roadblock” between existing BCERP practices governing research translation and dissemination efforts and failure to adopt the precautionary principle. This limits translation of research findings for the public.
- The value of translating and disseminating published research findings even if there are no identified actionable items from the research studies. Justification for this recommendation is related to: (a) the need to inform the public about the results, raise public awareness, and educate the target audiences; (b) the need to follow the precautionary principle; and (c) the fact that the studies were publicly funded.
- The perception by the advocates that most scientists do not always respect the advocates on the team.

## 4.2 Recommendations

The following recommendations are suggested for consideration during the second phase of the BCERP initiative:

- Develop and finalize a comprehensive research translation and dissemination plan to facilitate the translation of the research findings into practice. For example, the planning tool developed by the Agency for Healthcare Research and Quality (<http://www.ahrq.gov/qual/advances/planningtool.htm>) suggests the components of a dissemination plan should address the following:
  - What is going to be disseminated?
  - Who are the target audiences?
  - Are there any existing or potential dissemination partners?
  - How to convey the information?;
  - How to determine what worked in terms of translation and dissemination?
  - What is the dissemination work plan?
- Integrate the risk communication approach<sup>9</sup> into the social marketing process of disseminating the key research findings and establish guidelines for key message development and testing in the field.
- Consider the feasibility of the development of a science-based guidelines about environmental influences on breast cancer risk for the various target audiences, such as the general public and health care providers. An example of such established guidelines is the *Dietary Guidelines for Americans* (<http://health.gov/dietaryguidelines/2010.asp>)

<sup>8</sup> For further reference about research translation and key messages, see NCI, *Making Health Communication Programs Work*, 2008 (<http://www.cancer.gov/cancertopics/cancerlibrary/pinkbook>).

<sup>9</sup> For example, see Johnson, B and Fischhoff, B, *A Primer on Health Risk Communication Principles and Practices*, Agency for Toxic Substances and Disease Registry, CDC, 1985 (<http://www.astdr.cdc.gov/HEC/primer.html>).

published jointly by the U.S. Department of Agriculture and U.S. Department of Health and Human Services.

- Initiate a joint governmental effort through establish a working group consisting of members from NIH, CDC, and EPA to develop education programs about how to reduce environmental exposures that may affect breast cancer risk, such as chemical exposures and poor diets, for the target audiences, including school-aged children. An example is the National Cholesterol Education Program developed by the National Heart, Lung, and Blood Institute.
- Develop a social marketing plan for branding the BCERP and marketing the BCERP Web resources to the concerned public and target audiences.
- Promote collaboration among advocates and scientists in the BCERP through the establishment of additional funding, such as the recently awarded BCERP Opportunity Fund, to develop and implement science-based dissemination programs in the community and assess their impact and effectiveness through rigorous evaluation designs. The BCERP External Advisory Board could select the program showing exemplary results and provide an award to the collaborative group during the BCERP annual meetings.



## List of Acronyms

BCERC	Breast Cancer and the Environment Research Center
BCERP	Breast Cancer and the Environment Research Program
BCEWG	Breast Cancer and the Environment Working Group
BPA	Bisphenol A
CARRA	Consumer Advocates in Research and Related Activities
CME	Continuing medical education
COTC	Communication Outreach and Translation Core
COTR	Contracting Officer Technical Representative
NCI	National Cancer Institute
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health
NLM	National Library of Medicine
OAR	Office of Advocacy Relations
PSA	Public services announcement

## APPENDIX A

### List of Reviewed BCERP Published Literature: 2003–2010

#### 2003

Haslam SZ and Woodward TL, Host microenvironment in breast cancer development: Epithelial-cell-stromal-cell interactions and steroid hormone action in normal and cancerous mammary gland, *Breast Cancer Research*, 2003, 5: 208-215.

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## APPENDIX B

### List of Selected Websites Searched

#### *Government Sites:*

<http://cancer.gov>

<http://www.cancer.gov/cancertopics/types/breast>

<http://www.cancer.gov/cancertopics/pdq/prevention/breast/Patient>

<http://www.nlm.nih.gov/medlineplus/cancer.html>

<http://www.cdc.gov/cancer/breast/>

<http://ephtracking.cdc.gov/showCancerBcEnv.action>

<http://www.fda.gov>

<http://www.epa.gov>

#### *Non-government Sites:*

<http://www.breastcancerprevention.org/>

<http://www.breastcancerfund.org>

[http://www.causes.com/causes/210-campaign-for-cancerprevention?m=4cf8c0c4%recruiter\\_id=49802761](http://www.causes.com/causes/210-campaign-for-cancerprevention?m=4cf8c0c4%recruiter_id=49802761)

[http://breastcer.about.com/od/risk/a/bc\\_prevention.htm](http://breastcer.about.com/od/risk/a/bc_prevention.htm)

[http://www.ehow.com/facts\\_6152628\\_dioxins-breast-cancer.html](http://www.ehow.com/facts_6152628_dioxins-breast-cancer.html)

<http://health.msn.com/health-topics/breast-cancer/articlepage.aspx?cp-documentid=100170477>

<http://health.yahoo.net/channel/breast-cancer.html>

## APPENDIX C

### NIEHS and NCI BCERP Needs Assessment Study

#### Telephone Survey Questions

##### BCERP Researchers, COTC Members, and BCEWG Scientists

1. What basic concepts about environmental influences on breast cancer risk must the general public (parents, children, other caregivers) understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
2. What basic concepts about environmental influences on breast cancer risk must policy makers understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
3. What basic concepts about environmental influences on breast cancer risk must the media understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
4. At this stage of the BCERP, which is more appropriate – raising awareness about the potential influence of the environment on cancer or trying to change specific behaviors?
5. How should a BCERP research translation and dissemination program be structured and implemented? Who needs to be involved in the BCERP research translation and dissemination program and what would their roles be?
6. What are your criteria for determining if a research finding is ready to be translated for the public and disseminated? Would you want findings translated and disseminated even if there are no definitive outcomes? Why?
7. Were you involved in any of the translation efforts related to the BCERP research findings; if so, was it a positive or negative experience? Why?
8. Are there key BCERP research findings that have not yet been translated, but that are ready for translation? If so, what are they? Who are the target audiences for these messages?
9. Which key BCERP research findings are not yet ready for translation and why?
10. Do you have concern about any of the messages that have been developed from BCERP research findings to date?
11. What objectives, if met, are most likely to prepare target audiences to make informed decisions related to their environment and health (or, in the case of policy makers, health care providers, the media, etc., to help others make informed decisions)?

12. What are appropriate outcomes/evaluation metrics that may be used to measure or assess the effectiveness of any future BCERP-related informational materials disseminated to various target audiences? How would you define “useful or effective”?

## APPENDIX D

### NIEHS and NCI BCERP Needs Assessment Study

#### Telephone Survey Questions

##### BCERP and BCEWG Advocate Members

1. How long have you been involved in the Breast Cancer and the Environment Research Centers (BCERC)?
2. How familiar are you with the topic of environmental exposures and cancer risk, environmental exposure and breast cancer, and risk communication (especially as it relates to health or the environment)?
3. Have you used any BCERP outreach materials to date, and if so, how and with whom (e.g., advocates, scientists, health care providers, media, and the general public)? How useful have these materials been? How satisfied have you been with these materials?
4. Were you involved with the development of any of the BCERP outreach materials? If so, was the experience positive or negative, and why?
5. What basic concepts about environmental influences on breast cancer risk must the general public (particularly parents, children, other caregivers) understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
6. What basic concepts about environmental influences on breast cancer risk must health care providers understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
7. What basic concepts about environmental influences on breast cancer risk must policy makers understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
8. What basic concepts about environmental influences on breast cancer risk must the media understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?
9. What are the primary resources (e.g., government Web sites; academic/research institution Web sites; general search Web sites such as WebMD, Google, or Yahoo; libraries, etc.) you usually go to first when you are looking for information about environmental influences on cancer risk (especially breast cancer)?
10. Have you ever looked for information designed specifically for lay audiences about environmental influences on cancer risk? Breast cancer?
  - a. If so, what primary resources did you use?
  - b. Do you recall what specific topics you were looking for?
  - c. How did you use the resources you found?

- d. Do you consider these resources to be effective “as is” or are there any improvements that could be made to them to better meet your needs (e.g., content, format, etc.)? How would you define “useful or effective”?
  - e. Are there other topics related to cancer risk and environmental exposure that you would like to have available to you for use with your target audiences that you have been unable to find information about?
11. What are your criteria for determining if a research finding is ready to be translated for the public and disseminated? Would you want findings translated and disseminated even if there are no actionable items from the research findings? Why?
  12. How should a research and translation and dissemination program focused on environmental influences on breast cancer risk be structured and implemented? Who needs to be involved in such a research translation and dissemination program and what would their roles be?
  13. What strategies, goals, and guidelines are most likely to prepare target audiences to make informed decisions related to their environment and health (or, in the case of policy makers, health care providers, the media, etc., to help others make informed decisions)?
  14. What are appropriate outcomes and evaluation metrics that may be used to measure or assess the effectiveness of any future BCERP-related informational materials disseminated to various target audiences? How would you define “useful or effective” in relation to these metrics?
  15. What key BCERP research findings have already been translated, and for what target audiences?
  16. Are there key BCERP research findings that have not yet been translated, but that are ready for translation? If so, what are they? Who are the target audiences for these messages?
  17. Which key BCERP research findings are not yet ready for translation and why?
  18. Do you have concerns about any of the messages that have been developed from BCERP research findings to date?

## APPENDIX E

### NIEHS and NCI BCERP Needs Assessment Study

#### Telephone Survey Questions

##### NCI Consumer Advocates in Research Related Activities Volunteers

1. How familiar are you with the topic of environmental exposures and cancer risk (especially breast cancer risk), and risk communication (especially as it relates to health and the environment)?
2. Before being contacted for this interview, were you aware of the NIEHS- and NCI-sponsored Breast Cancer and the Environment Research Program (BCERP)? If yes, have you used any BCERP outreach materials to date? How have you used them and with whom? How useful have these materials been? How satisfied have you been with these materials?
3. What basic concepts about environmental influences on breast cancer risk do you think the general public (particularly parents, children, other caregivers) understand? Do materials that address these concepts exist already? What do you think are the most effective formats for communication materials for this target audience?
4. What basic concepts about environmental influences on breast cancer risk must health care providers understand? What do you think are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?
5. What basic concepts about environmental influences on breast cancer risk must policy makers understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?
6. What basic concepts about environmental influences on breast cancer risk must the media understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?
7. What are the primary resources (e.g., government Web sites; academic/ research institution Web sites; general search Web sites such as WebMD, Google, or Yahoo; libraries, etc.) you usually go to first when you are looking for information about environmental influences on cancer risk (especially breast cancer)?
8. Have you ever looked for information designed specifically for lay audiences about environmental influences on cancer risk? Breast cancer?
  - a. If so, what primary resources did you use?
  - b. Do you recall what specific topics you were looking for?
  - c. How did you use the resources you found?
  - d. Do you consider these resources to be effective “as is” or are there any improvements that could be made to them to better meet your needs (e.g., content, format, etc.)? How would you define “useful or effective”?

- e. Are there other topics related to cancer risk and environmental exposure that you would like to have available to you for use with any of the target audiences referenced in previous questions that you have been unable to find information about?
9. What are your criteria for determining if a research finding is ready to be translated for the public and disseminated? Would you want findings translated and disseminated even if there are no actionable items from the research findings? Why?
  10. How should a research and translation and dissemination program focused on environmental influences on breast cancer risk be structured and implemented? Who needs to be involved in such a research translation and dissemination program and what would their roles be?
  11. What strategies, goals, and guidelines are most likely to prepare the general public to make informed decisions related to their environment and health (or, in the case of policy makers, health care providers, the media, etc., to help others make informed decisions)?
  12. What are the appropriate outcomes and evaluation metrics that may be used to measure or assess the effectiveness of any future BCERP-related informational materials disseminated to various target audiences? How would you define “useful or effective” in reference to these metrics?

## APPENDIX F

### NIEHS and NCI BCERP Needs Assessment Study

#### Telephone Survey Questions

##### NIH Staff with Communications Expertise

1. How familiar are you with the topic of environmental exposures and cancer risk (especially breast cancer risk), and risk communication (especially as it relates to health and the environment)?
2. Before being contacted for this interview, were you aware of the NIEHS and NCI Breast Cancer and the Environment Research Program (BCERP)?
3. Have you ever looked for information about environmental influences on cancer risk, especially on breast cancer, designed specifically for lay audiences?
  - (a) If so, what primary sources did you use?
  - (b) Do you recall what specific topics you were looking for?
  - (c) How did you use the resources you found?
  - (d) Do you consider these resources to be effective “as is” or are there any improvements that could be made to them to better meet your needs (e.g., content, format, etc.)? How would you define “useful” or “effective”?
4. Are you aware of any existing government sources of information specifically designed for lay audiences related to environmental influences on breast cancer risk?
  - (a) If so, what are they?
  - (b) How effective do you think they are as risk communication tools and why?
  - (c) Do you feel like the content is current or out of date?
  - (d) How can the existing information be improved?
5. What do you think are the key messages the Breast Cancer and the Environment Research Program should focus on?
6. In your experience, who are the key target audiences the government is trying to reach with information about the role of the environment and cancer, especially related to breast cancer risk?
  - (a) In your opinion, which two target audiences are the most important to reach?
  - (b) Which two are least important to reach?
7. What basic concepts about environmental influences on breast cancer risk must policy makers understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?



Similarly, what basic concepts about environmental influences on breast cancer risk must health care providers understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?

8. What basic concepts about environmental influences on breast cancer risk must the media understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?

As for the general public (particularly parents, children, and other care givers), what basic concepts about environmental influences on breast cancer should they understand? What are the most effective formats for communication materials for this group of target audience? Do these materials exist already?

9. What are your criteria for determining if a research finding is ready to be translated for the public and disseminated? Would you want findings translated and disseminated even if there are no actionable items from the research findings? Why?
10. How should a research and translation and dissemination program focused on environmental influences on breast cancer risk be structured and implemented? Who needs to be involved in such a research translation and dissemination program and what would their roles be?
11. How would you recommend integrating any existing governmental messages about environmental influences on breast cancer risk with new messages over the next few years from the BCERP, advocacy organizations, etc.?
12. What strategies, goals, and guidelines are most likely to prepare the general public to make informed decisions related to their environment and health (or, in the case of policy makers, health care providers, the media, etc., to help others make informed decisions)?
13. What key behaviors will demonstrate that the research translation and dissemination activities have been effective?

## APPENDIX G

### NIEHS and NCI BCERP Needs Assessment Study

#### Telephone Survey Questions

##### NIH Staff Involved With the BCERP Activities

1. How familiar are you with the topic of environmental exposures and cancer risk (especially breast cancer risk), and risk communication (especially as it relates to health and the environment)?
2. Have you ever looked for information about environmental influences on cancer risk, especially on breast cancer, designed specifically for lay audiences?
  - (a) If so, what primary sources did you use?
  - (b) Do you recall what specific topics you were looking for?
  - (c) How did you use the resources you found?
  - (d) Do you consider these resources to be effective “as is” or are there any improvements that could be made to them to better meet your needs (e.g., content, format, etc.)? How would you define “useful” or “effective”?
3. Are you aware of any existing government sources of information specifically designed for lay audiences related to environmental influences on breast cancer risk?
  - (a) If so, what are they?
  - (b) How effective do you think they are as risk communication tools and why?
  - (c) Do you feel like the content is current or out of date?
  - (d) How can the existing information be improved?
4. What do you think are the key messages the Breast Cancer and the Environment Research Program should focus on?
5. In your experience, who are the key target audiences the government is trying to reach with information about the role of the environment and cancer, especially related to breast cancer risk?
  - (a) In your opinion, which two target audiences are the most important to reach?
  - (b) Which two are least important to reach?
6. What basic concepts about environmental influences on breast cancer risk must policy makers understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?

Similarly, what basic concepts about environmental influences on breast cancer risk must health care providers understand? What are the most effective formats for communication materials for this target audience? Do these materials exist already?

7. What basic concepts about environmental influences on breast cancer risk must the media understand? What are the most effective formats for communication materials for this target audience? Do materials that address these concepts exist already?

As for the general public (particularly parents, children, and other care givers), what basic concepts about environmental influences on breast cancer should they understand? What are the most effective formats for communication materials for this group of target audience? Do these materials exist already?

8. What are your criteria for determining if a research finding is ready to be translated for the public and disseminated? Would you want findings translated and disseminated even there are no actionable items from the research findings? Why?
9. How should a research and translation and dissemination program focused on environmental influences on breast cancer risk be structured and implemented? Who needs to be involved in such a research translation and dissemination program and what would their roles be?
10. How would you recommend integrating any existing governmental messages about environmental influences on breast cancer risk with new messages over the next few years from BCERP, Advocacy organizations, etc.?
11. What strategies, goals, and guidelines are most likely to prepare the general public to make informed decisions related to their environment and health (or, in the case of policy makers, health care providers, the media, etc., to help others make informed decisions)?
12. What key behaviors will demonstrate that the research translation and dissemination activities have been effective?
13. Based on your knowledge, what key BCERP research findings have already been translated, and for what target audiences? Are there any data available indicating the effectiveness of any translated findings? If so, what are the metrics describing effectiveness?
14. Are there key BCERP research findings that have not yet been translated, but are ready for translation? If so, what are they? Who are the target audiences for these messages?
15. Which key BCERP research findings are not yet ready for translation and why?