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# The Ribbon

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## The Breast Cancer Core Questionnaire Project

The accompanying article, Fundamentals for Interpreting Breast Cancer Epidemiology, discusses some of the important features of epidemiologic studies. Increasingly, researchers are combining the data from multiple studies and analyzing this data in aggregate to increase statistical power and strengthen conclusions. Researchers doing these "meta-analyses" need to standardize measurement of important variables across studies in order to facilitate analysis. Fortunately, there is an exciting project taking place that may help mitigate this major stumbling block in understanding breast cancer risk factors.

### The Breast Cancer Core Questionnaire Project

The National Action Plan on Breast Cancer (NAPBC), coordinated by the U.S. Public Health Service's Office on Women's Health, is a public-private partnership whose key objective is to stimulate rapid progress in eradicating breast cancer by "jump-starting" innovative, long-term efforts in six priority areas. Each priority area has a corresponding Working Group, including a Breast Cancer Etiology Working Group ("etiology" is the branch of medicine dealing with the causes of a disease). A main activity of the Etiology Working Group is to develop a "core questionnaire" to improve the availability, quality, and comparability of data on risk factors for breast cancer. This Breast Cancer Core Questionnaire (BCCQ) Project is a collaborative effort of NAPBC, the National Cancer Institute (NCI), and Temple University's Institute for Survey Research (ISR).

The unique scientific features of the BCCQ support this goal of improving the epidemiologic study of breast cancer risk factors. Its six questionnaire modules integrate the biomedical and behavioral sciences, comprehensively covering the known and suspected risk factors for breast cancer. These modules are designed with three levels of increased depth, with designated "core questions."

The six modules of the BCCQ, and the leader of each respective module's design team are:

Medical and Reproductive History, Janet Daling, Ph.D., Fred Hutchinson Cancer Research Center Sociodemographic and Cultural Factors, Nancy Krieger, Ph.D., Harvard School of Public Health Occupational Exposures, Ann Aschengrau, Sc.D., Boston University School of Public Health and Julia Brody, Ph.D., Silent Spring Institute Environmental Exposures, Steven Stellman, Ph.D.,

**Environmental Exposures,** Steven Stellman, Ph.D., M.P.H., American Health Foundation

**Personal Behaviors and Lifestyle,** Leslie Bernstein, Ph. D., University of Southern California

**Diet and Nutrition,** *Lenore Kohlmeier, Ph.D., University of North Carolina* 

### **Unique Features of the BCCQ Modules**

Design teams with wide expertise and diversity developed these modules, which both stand alone and complement one another. For example, as Dr. Ellen Werner of Temple University's Institute for Survey Research explained at a recent presentation about the BCCQ, the Medical and Reproductive History module, which seeks to accurately capture information on known risk factors for breast cancer, will help researchers understand the possible confounding relationships between some of these known risk factors, and suspected risk factors. Characteristics such as parity may potentially confound analyses relating occupational, environmental, or other exposures with the risk of breast cancer.

Similarly, the Sociodemographic and Cultural Factors module seeks to further clarify some relationships that have not been completely understood to date. Dr. Krieger has designed this module to provide more nuanced and complete information on factors such as socioeconomic position, race/ethnicity/religious affiliation, and family status. For example, the module addresses the possible relationships between religious participation and affiliation, and lifestyle questions such as alcohol consumption and dietary patterns.

The modules on Occupational and Environmental Exposures have the potential to make significant contributions to the many research gaps in this area. As Dr. Brody pointed out from her experience contributing to the development of the Occupational Exposures module, very little has been done thus far looking at women's work histories and breast cancer incidence. The Occupational Exposures questionnaire is designed to obtain a comprehensive adult occupational history, addressing all paid and unpaid jobs held for at least six months, since age 16.

A highlight of the Environmental Exposures module is an extensive questionnaire on residential history, which includes a very detailed pesticide section. This questionnaire seeks to obtain information on pesticides used in and around any of the respondent's homes, yards, or gardens, by the respondent, other household members, or professionals. Importantly, questions concerning insect repellents on the skin, hair and clothing are included, as are pet treatments.

The Personal Behaviors and Lifestyle module covers the areas of exercise, smoking (including "passive

smoking"), and "over the counter" and other drug use. The other major lifestyle area, diet and nutrition, is covered in a module which includes detailed questions that will provide important information in promising areas of breast cancer risk reduction: fruit, vegetable and soy consumption.

### **Unique Organizational Features** of the BCCQ Project

In addition to the individual design team which developed each module, there is a review team, and together these groups represent a wide range of universities, federal government institutes and agencies, regional health departments and community liaisons. Breast cancer activists have also been fully involved in the design, review and focus group evaluation of the modules.

In September 1996, these diverse participants in the project met at a workshop to finalize drafts of the modules and identify core questions within each module that will comprise the core questionnaire. The focus groups, conducted by Dr. Werner between November 1996 and September 1997, discussed whether the items in each questionnaire were relevant, clear, unambiguous, comprehensible, and acceptable. Currently, each module and the core questionnaire are undergoing revisions to incorporate changes from these focus groups discussions. Dr. Werner will also develop an instructions manual that will be available with the completed questionnaire in May 1998. Researchers who are interested in using the modules in their studies should contact Dr. Werner at (202) 973-2820. For copies of the final report on the focus groups, contact Joan Becker at (202) 401-9587.

