

Black Women's Health Study



BOSTON UNIVERSITY
SCHOOL OF MEDICINE



HOWARD UNIVERSITY
COLLEGE OF MEDICINE

July 1999 Newsletter



BWHS staff

**WORKING TOGETHER TO IMPROVE
THE HEALTH OF BLACK WOMEN**

WHAT'S GOING ON IN THE BWHS?

The 1999 questionnaire was mailed in April. We are pleased to tell you that 28,000 BWHS participants have already filled it out and returned it to us. If you haven't received a 1999 questionnaire, please let us know and we'll send you one. Our toll-free number is 1-800-786-0814. Your participation is very important to the success of the study, so we urge you to take 15 or 20 minutes to fill out the questionnaire. Thanks.

THE SAME QUESTIONS — AGAIN

You have received a BWHS health questionnaire every two years since 1995. Each questionnaire asks some of the same questions, such as level of physical activity or oral contraceptive use. Habits change over time, and asking about these factors every two years means participants will be correctly classified for each time period. The question on whether you have had any of a list of major illnesses is also repeated so that all new illnesses can be counted and included in analysis.

Confidentiality

As soon as the questionnaires are received at our office, the sheet with personal information is detached from the rest of the questionnaire and stored separately. Published information provides group statistics only and never individual information. Furthermore, by law, the Black Women's Health Study is prohibited from providing participant information to outside sources.

NEW QUESTIONS

We have responded to comments by many of you about the need to study mental health by adding questions on emotions in your daily life. We have also added sections on weight loss and family history of major illnesses.

Are there health issues that you think the BWHS should be studying but isn't? Please let us know. Write or call us toll-free at 1-800-786-0814.

SCIENTIFIC PRESENTATIONS FROM THE BWHS

The Society for Epidemiologic Research is the largest organization of epidemiologists in the world, with members from the U.S. and other countries as well. The annual meeting held this June in Baltimore provided an opportunity to present data from the BWHS.

Keeping Up With BWHS Participants. Delia Russell, project manager of the BWHS, presented “Methods for Follow-up in a Mobile Population.” The mobility of BWHS participants is remarkable. Since the BWHS began in 1995, 54% of you have moved at least once, and 11% have moved 4 or more times. Women under age 30 moved the most—70% changed addresses—and women over 50 moved least, but still quite a bit—40% moved. Because the validity of results from a follow-up study like the BWHS is crucially dependent on getting information from as many participants as possible, we need to know where you are. We have had good success in obtaining new addresses from the “contact person” whose name you provided (usually a relative or a friend), and from the postal service. The Newsletters that we send you twice a year always have a postcard for you to send us address changes—these have been an excellent source of new addresses, over 5,000. Email addresses should be useful in the future as more and more of you obtain them. Don’t forget that you can call us, toll free, at 1-800-786-0814. If you are planning to move, please let us know where you are going!

Breast Cancer and Stature. Dr. Julie Palmer, one of the BWHS scientific investigators, presented data suggesting that taller BWHS participants may have a slightly higher risk of breast cancer than shorter ones. Other studies have found this as well. The difference in risk between tall and short women is too small to be of any importance to individuals, but it is of scientific interest because it may provide some clues about the causes of breast cancer. One theory is that taller women simply have more breast cells on average than shorter women, providing more opportunity for a mutation to occur and a cancer to grow. Another theory is that certain hormones related to height also increase cell division, again providing more opportunity for cancer to occur. Being tall may be a slight disadvantage in terms of breast cancer, but it’s an advantage in terms of heart disease—tall women have a slightly lower risk of having a heart attack than shorter women. A possible explanation is that the coronary arteries of tall women tend to be larger in circumference than those of short women and are thus less prone to becoming blocked.

UPDATE ON THE BWHS LOGO

In the January 1999 Newsletter we invited you to submit ideas for a BWHS logo. Here's a small sample of the BWHS participants who responded. **Marilou Vance** of Sedona, AZ, retired after owning her own graphics business for 14 years. She created a design based on her experience with black women healers, and she has opened her home to healers as a place of reflection and rejuvenation. **Leanne Wharton** creates her own series of greeting cards and exhibits her commissioned work in the Chicago area. Her love of art began at age 5 when her mother gave her a paint by numbers set. Her design is based on a vision of black women creating healthier lives for themselves. **June Guillory** of Los Angeles, a retired administrative assistant and mother of four adult sons, is a poet. She found inspiration for a logo design in a bouquet of balloons.



The designs are still coming in. We hope to have chosen one by the millennium.

EVERY RESPONSE MAKES A DIFFERENCE

With 64,500 women in the BWHS, you may wonder how important your response is. The fact is, your response is very important. Without your input, the conclusions we reach may be wrong. As a simple example, consider a survey to find out about the smoking habits of 100 people, of whom 20 are smokers and 80 nonsmokers. If 10 smokers and 78 nonsmokers respond to a questionnaire about their smoking habits, we will conclude that the smoking rate is 10 out of 88, or 11% instead of the true rate of 20%. The higher the response, the less the chance for error. Thus, if 18 smokers and 78 nonsmokers respond (96 out of the original 100 people), the smoking rate will be calculated as 18 of 96, or 19%, very close to the true rate of 20%. Keeping the number of nonrespondents as low as possible is critical to drawing correct conclusions from the BWHS data.

QUESTIONS AND ANSWERS

Q I have been diagnosed with lupus. Recently the BWHS asked permission to obtain copies of my medical records. Why?

A Medical record information is used to determine how accurately diseases are reported, and to classify different types of particular diseases. We request only the portion of the medical record that applies to the disease. As always, the information will be kept strictly confidential and used only in statistical analyses.

Q I filled out a questionnaire in 1995, but not in 1997. Do you want me to fill out a 1999 questionnaire?

A Yes. Please do. Even without the 1997 information, the information that you provide in 1999 will be very useful. Please remember that only those women who completed the 1995 baseline questionnaire may participate in the BWHS.

Q How long will the BWHS continue?

A At least 5 more years, and probably more. The National Institutes of Health funds studies for, at most, 5 years at a time. At the end of that period, investigators must apply for a continuation. We have just applied for a continuation of the BWHS. Over the course of follow-up, the number of women affected by any particular illness will increase, allowing for more informative analysis. The longest-running large follow-up study of health yet conducted is the Nurses' Health Study, in which 98% of the participants are white. The study has published 300 research articles over the course of 25 years.

Q Why do you send health questionnaires every two years?

A Updated information is needed on factors that can change over time, like exercise, weight, and cigarette smoking. The more accurate the information is, the more informative will be the results based on it. We also need to learn about the occurrence of illness among participants.