

Black Women's Health Study



BOSTON UNIVERSITY
SCHOOL OF MEDICINE



HOWARD UNIVERSITY
COLLEGE OF MEDICINE

January 2001 Newsletter

**WATCH FOR THE 2001 BWHS HEALTH
QUESTIONNAIRE COMING IN MARCH**

**VISIT THE BWHS WEBSITE AT
www.bu.edu/bwhs**

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



The Boston staff is moving in late spring to a new office just a mile away from our present office. Our new address is 1010 Commonwealth Avenue, Boston, MA 02115. The telephone number is still 1-800-786-0814. Please let us hear from you if you move.

The 2001 BWHS Questionnaire will be sent in late March. Please fill it out and return it to us as soon as you can. And let us know if you don't receive one.

The BWHS website is now in operation.

Please visit it at

www.bu.edu/bwhs

for information on the BWHS
and on research results.



THE WHY AND HOW OF THE BWHS

Previous BWHS newsletters have touched on the purposes of the study. This issue is devoted to giving detailed answers to the questions you have asked: what are the goals of the BWHS, how did it begin, how does it work, how long will it run, what will it produce.

THE WHY OF THE BWHS

Ten years ago we knew that black women were more likely to develop many health problems, and to die of them, than white women. We also knew that most of the previous studies of women's health had included only small numbers of black women or none at all. We felt that improving the health of black women required more knowledge of the causes of these health problems, and that more knowledge meant more research. We decided that we would do our best to take the lead in carrying out that research.

THE STUDY DESIGN

We wanted to design a study that would gather information on many conditions that affect black women—breast cancer, lupus, premature birth, hypertension, colon cancer, diabetes...the list was long. To study many diseases at the same time, the best possible design is a “follow-up” study. A follow-up study enrolls participants and then follows them over time. When the participants enter the study, they provide information on factors that might influence health and disease, such as contraceptive use, cigarette smoking, and diet. At regular intervals, participants provide updated information on these factors (because the factors may change over time), and also on any illnesses they develop.

STARTING THE BWHS

To get funding for the BWHS, we submitted a grant proposal to the National Institutes of Health (NIH). A proposal must contain evidence that the proposed study can be carried out. Once we had decided that a follow-up design was best, we had to demonstrate that it would work. We designed a questionnaire that asked about age, education, contraceptive use, smoking, and other factors that might be related to health and disease. The National Education Association allowed us to mail questionnaires to a sample of black female teachers; the federal government delivered questionnaires through their personnel offices to a sample of black female employees; and *Essence* magazine gave us access to a sample of subscribers after we had paid a fee. The completed questionnaires that were returned to us showed clearly that enough black women were willing to provide useful and accurate health information to make a study feasible. After submitting a detailed grant proposal to NIH, review of the proposal and revision, we received funding. The entire process, from developing the idea and conducting the studies to show that our study would work to receiving funding for the BWHS took about four years. With the funding secured, in 1995 we sent health questionnaires to subscribers to *Essence* magazine, women who had participated in our feasibility studies, members of the Black Nurses' Association, and friends and relatives of respondents. The 64,500 women who returned completed questionnaires became the members of the BWHS.

DAY TO DAY ON THE BWHS

We design a new health questionnaire every two years. Questionnaires contain some of the same questions each time (to get updated information), and some new questions about additional factors. The first mailing of the questionnaire occurs in the spring. Our study results, and the continuation of the study, depend upon collecting responses from as many of the original 64,500 participants as possible, so we mail the questionnaire multiple times to those who have not yet returned it. When your questionnaire is received, it is handled by a staff of three supervisors and eight research assistants who:

- ★ **RECORD RECEIPT**—questionnaires are recorded as received within 24 hours;
- ★ **REMOVE THE LAST PAGE**—the last page is removed so that identifying information is not connected with the data;
- ★ **EDIT**—each questionnaire is checked for your questions and comments and to make sure that your responses are marked darkly enough to be “seen” by the scanner;
- ★ **SCAN**—each questionnaire is sent through a scanner that records the responses and adds them to a computer file of all BWHS responses;
- ★ **CODE**—responses that you have written in, such as medications, are reviewed and coded; and
- ★ **TEST**—the responses in our data file are examined to make sure that we have accurately recorded all that you have reported.

The entire process, from receipt of the first questionnaires to having the data ready for analysis, takes about two years. It is only then that the research team can carry out the statistical analyses that will provide information on the causes and preventives of disease. Our staff also works on several other tasks. Participants are contacted to ask for consent to review their medical records. When consent is given, we send for the records to gather relevant information about the illness. We also work hard to locate women who have moved; some BWHS participants move quite often and the postal service is not always able to give us accurate new addresses, so we use other means to locate these “lost” participants. We learn about deaths from friends, relatives, the postal service, and the National Death Index. We conduct special studies within the BWHS. Four hundred women participated in a diet validation study that assessed how well a series of questions on usual diet reflected what women were actually eating. Several hundred BWHS participants are being invited to participate in a validation study of physical activity, and some participants have provided cheek cell samples for a biological study.

HOW LONG WILL THE BWHS LAST?

The BWHS will last at least 10 years, and we hope much longer. Our first NIH grant for the BWHS was for five years. Funding has been continued for an additional five years. How long the BWHS should last depends on what we want to learn. For example, if we want to learn about hypertension, a common illness, five years is enough. Over the first five years of the BWHS, thousands of participants developed this condition, enough to be able to assess whether a wide range of factors are related to it. But rare illnesses are a very different story. Take lupus, for example. This illness occurs much more commonly among black women than among other ethnic groups, and yet it is still a rare illness even among black women. In the first five years of the BWHS, about 100 women developed lupus. After 10 years, that number is expected to reach about 200. That's enough to start studying lupus, but not enough for final answers. And even for common illnesses, new questions arise that require collecting further information from participants. Because many quite important and serious illnesses are rare, and because new questions arise about common illnesses, some follow-up studies of white women, such as the Nurses' Health Study, are now in their 25th year. The BWHS will continue for as long as the participants and NIH think the study is worthwhile and as long as we can obtain funding.

WHAT WILL THE BWHS TELL US?

The BWHS has already produced important information. We've told you about the research results in past newsletters, and you can visit our **Website** (www.bu.edu/bwhs) for further information. Here are some of the things we'd like to learn from the BWHS:

- ★ Why does breast cancer occur more commonly among young black women than among young white women?
- ★ Does exercise influence the occurrence of breast cancer in black women?
- ★ Does diet influence the occurrence of breast cancer in black women? If so, what nutrients or foods?
- ★ Why does lupus occur more commonly in black women?
- ★ Why does premature birth occur more commonly among black babies?
- ★ Do experiences of racism affect the occurrence of various illnesses in black women?