Participation in the Black Women’s Health Study

The Black Women’s Health Study (BWHS) is a research study led by Dr. Lynn Rosenberg and Dr. Julie Palmer at Boston University and Dr. Lucile Adams-Campbell at Georgetown University. BWHS researchers also work with health researchers from other institutions when expertise in particular areas is needed. Advice is provided by an advisory board knowledgeable about the health issues of African-American women. Follow-up questionnaires are sent every 2 years to you and the 59,000 other participants in the BWHS to update information and learn about the occurrence of illnesses like cancer, heart disease, stroke and lupus. Women who develop certain illnesses will be asked for permission to review their medical records pertaining to that illness. Cancer registry and Medicare/Medicaid data will be obtained by study investigators. Participants who do not wish this information to be obtained should notify the BWHS staff.

There is no harm to you other than the possibility of discomfort from answering sensitive questions.

The chief benefit will be to the public health, in that the study will provide information on causes of common cancers and other illnesses in black women. Many of the illnesses to be studied affect black women disproportionately. The information provided by the Black Women’s Health Study could be useful in efforts to prevent illness.

All survey data are kept strictly confidential and used only in statistical analyses. All activities are overseen by the Institutional Review Board of Boston University. The study is protected by a certificate of confidentiality from the U.S. Department of Health and Human Services. With this Certificate, the researchers cannot be forced to disclose information that may identify you in any federal, state, or local civil procedures.

You may obtain further information about your rights as a research subject by calling the Office of the Institutional Review Board of Boston University Medical Center at 617-638-7207. If you have any questions or concerns at any time you may contact Dr. Lynn Rosenberg or Black Women’s Health Study staff at 800-786-0814 or 617-734-6006. The investigator or a member of the research team will try to answer all of your questions.

Taking part in this study is voluntary. You have the right to refuse to participate in any part of this study. At any time you may choose not to participate either by deciding not to fill out the questionnaire or by asking us to remove your name from our mailing list.