



Working together to improve the health of Black women

- Participant Advisory Group
- Breast cancer in Black women in the U.S. and Africa
- Ethical human research
- Recent BWHS findings
- New BWHS Investigators

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GREETINGS FROM THE BWHS

Greetings. We hope you are well. The BWHS, now in its 23rd year, is going strong. In the fall of 2017, funding for the BWHS was renewed for another 5 years. This was made possible by the long-term dedication of BWHS participants. Congratulations! We are very happy to continue working with you to improve understanding of health and illness in Black women.

Thank you to the more than 34,000 participants who have completed the 2017-2018 BWHS health survey. Participants who have not completed the health survey, which is only 2 pages long, can do so on paper, online (www.bu.edu/bwhs) or by letting us know that you'd like to complete the survey by telephone (call 1-800-786-0814 or send an email to bwhs@bu.edu).

This newsletter describes a talk that Dr. Julie Palmer, a BWHS leader, gave on breast cancer in Black women at the International Agency for Research on Cancer; new studies of breast cancer among Black women in Africa; issues involved in conducting ethical research studies; new research results from the BWHS; and two new BWHS investigators.

Join the Participant Advisory Group

Several years ago, we put a notice in a BWHS newsletter inviting BWHS participants to join a **Participant Advisory Group (PAG)**, which would advise the BWHS team on research directions and issues, such as how to phrase questions on the health surveys. Several hundred BWHS participants volunteered. From time to time we have asked the PAG for advice. Each time, some members have responded, and each time the advice has been very helpful. New issues of importance to conducting research on Black women's health have arisen, such as data sharing and consent issues. We invite BWHS participants who are interested in giving their opinion on these or other research questions to send us an email. We will add you to the PAG.

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BREAST CANCER IN BLACK WOMEN IN THE U.S. AND AFRICA

In September 2018 Dr. Julie Palmer spoke at the International Agency for Research on Cancer (IARC) about breast cancer in Black women in a talk entitled "More than genes: social and behavioral factors influence racial disparities in breast cancer". IARC is part of the World Health Organization of the United Nations and is interested in cancer worldwide. Most of Julie's talk involved BWHS research. In the U.S., Black women are much more likely than White women to develop the more aggressive type of breast cancer called estrogen receptor negative (ER-). The reasons for this difference are not clear, but non-genetic factors are involved. Research from the BWHS and others indicates that the chance of developing this type of breast cancer can be reduced by breastfeeding, eating more fruits and vegetables, and preventing type 2 diabetes.

As in the U.S., breast cancer is the most common female cancer in sub-Saharan Africa. In recent years deaths from breast cancer have increased greatly in that region. There has not been enough research to determine whether ER- breast cancer occurs more commonly among African women. Because of increased interest in these questions, large breast cancer studies have been started. In Ghana, Black women with newly occurring breast cancer are being compared with women without breast cancer. A study of breast cancer survivors (the African Breast Cancer—Disparities in Outcomes Study) is recruiting women with breast cancer in Namibia, Nigeria, South Africa, Uganda, and Zambia. The hope is to learn about factors that increase survival among breast cancer patients in Africa.



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ETHICAL HUMAN RESEARCH



The Internal Revenue Service, banks, and credit card companies have financial information on many individuals. Mapping applications, like Google Maps, know where we live. Numerous companies track our activities based on our use of the internet and social media. In contrast, scientific research has strong protections for participants and the privacy of information that they share.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was formed in 1974 after the Tuskegee syphilis study abused the rights of the Black men who participated. The Commission's Belmont Report details several guiding principles for ethical research:

Respect for persons: people should be given sufficient information to decide if they wish to participate.

<u>Beneficence:</u> research should minimize risks to participants and maximize benefits to participants and society.

Justice: the burdens and benefits of the research should be distributed fairly.

Institutional Review Boards (IRBs) at research institutions across the U.S. follow these principles and approve only those studies that they judge to be ethical. All BWHS research is approved by a Boston University IRB. Some research areas require many thousands of participants, such as genetic studies that assess millions of genetic variants. The required sample sizes can only be achieved if data are combined together from multiple studies through data sharing. Data sharing makes scientific sense, and it makes ethical sense when the people who contributed the data agree. Blood samples collected in the BWHS provide an example of how sharing can occur. Participants indicated on the blood sample consent form whether genetic information from their blood samples could be shared anonymously (that is, without any personal identifiers) through a database to which qualified researchers could apply to conduct analyses of the genetic data. About two-thirds of BWHS participants who gave blood said, "Yes, my data can be shared through the database", while around one-third said, "No, share my genetic data only with BWHS scientists and their collaborators." Both ethics and science are served when the wishes of the participant are honored and when studies are large enough to answer important scientific questions.

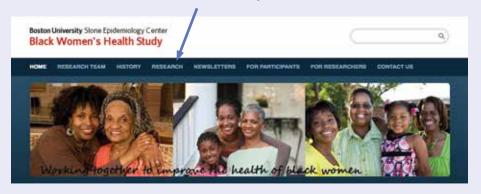
BWHS RESEARCH FINDINGS

Frequently Asked Question by BWHS Participants:

Where can I read about BWHS research findings?

Answer:

On the BWHS website (www.bu.edu/BWHS) under Research



Here are some recent findings:

Perceived racism and incident diabetes in the Black Women's Health Study. Racism has been shown to have numerous adverse effects on the health of people who experience it. In the BWHS, experiences of everyday racism (everyday occurrences such as receiving poorer service) and institutional racism (such as being discriminated against for housing) were related to increased risk of developing type 2 diabetes. Excess weight associated with racism accounted for about half of the increased diabetes risk. Bacon KL et al. Diabetologia 2017.

Inflammatory signatures distinguish metabolic health in African American women with obesity. Type 2 diabetes (T2D) associated with obesity is an inflammatory condition that increases risk of heart disease and other conditions. We examined blood-based cytokines to develop inflammation scores for three groups of women within the BWHS: obese women with T2D and hypertension, obese women without T2D or hypertension, and lean women without T2D or hypertension. Inflammation profiles differed, with those of obese women without T2D or hypertension somewhat similar to those of lean women without T2D or hypertension. These analyses suggest that blood-based cytokine profiles are a useful way to discern inflammation and T2D risk among women with obesity, and would be a useful addition to personalized risk assessment. Denis et al. PLoS One, 2018.

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BWHS RESEARCH FINDINGS

Breastfeeding and the risk of endometrial cancer-a pooled analysis from the Epidemiology of Endometrial Cancer Consortium. In a pooled analysis of multiple studies, including the BWHS, breastfeeding was associated with a lower risk of endometrial cancer (cancer of the lining of the uterus). There are many benefits of breastfeeding to the baby. These findings on endometrial cancer suggest that a reduction in risk of this cancer can be added to the list of benefits to the mother associated with breastfeeding. Jordan SJ et al. Obstet Gynecol, 2018.

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Religious and spiritual coping and risk of incident hypertension in the Black Women's Health Study. It is unclear if religious practices affect health. BWHS participants provided information on their religious practices on the 2005 health questionnaire. High involvement of religious/spiritual coping with stressful events compared with no involvement of religious/spiritual coping was associated with reduced risk of high blood pressure in the BWHS, but more frequent prayer was associated with increased risk of high blood pressure. The reason for these findings are unknown and need further examination. Cozier et al. Ann Behav Med, 2018.

Admixture mapping and fine-mapping of birth weight loci in the Black Women's Health Study. Black mothers are more likely than other mothers to give birth to a baby with a low birthweight. Low birthweight is associated with adverse health outcomes in the baby, including poorer survival. In the BWHS, we identified multiple genetic variants associated with low birth weight. These may help to explain race-associated birth weight differences. It might be possible in the future to monitor women who are at high risk of giving birth to low birthweight babies by identifying those women with a genetic profile pointing in that direction. Ochs-Balcom et al. Hum Genet, 2018.

Relationship of cigarette smoking and alcohol consumption to incidence of systemic lupus erythematosus in the Black Women's Health Study. Black women develop systemic lupus erythematosus (lupus) more than other women (and men) for reasons that are still unknown. In the BWHS, we found that cigarette smokers had an increased risk, while moderate alcohol drinkers had a reduced risk. These findings are consistent with several plausible biologic mechanisms but do not explain why Black women are at higher risk. Cozier et al. Arthritis Care Res, 2018.

NEW INVESTIGATORS JOIN BWHS TEAM



Shanshan
Sheehy, MD,
ScD, has joined
the BWHS team
of investigators.
She earned a
doctoral degree
in epidemiology
based on
work involving
survivors of

heart attacks. She also has training in medicine. Shanshan's chief research interest concerns causes of cardiovascular disease, such as heart attacks and stroke. In addition to this research, she will be helping to lead the effort to obtain information on diagnoses from Medicare health data.



Gary R. Zirpoli, PhD, has also joined the BWHS team of investigators. He earned his doctoral degree in epidemiology based on work involving breast cancer

survivors. He also has extensive training in biostatistics and mathematics. His first research with the BWHS will involve interactions of genes and environment to affect breast cancer risk. He will also be in charge of keeping track of biological specimens contributed by BWHS participants to the research effort.



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