

White House Launches Initiative on Women's Health Research

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An important new initiative focused on women's health research – defined as “the study of health across a woman's lifespan in order to preserve wellness and to prevent, diagnose, and treat disease” – was recently kicked off in the United States. On November 13, 2023 the White House announced the Initiative on Women's Health Research, to be led by First Lady Jill Biden and the Gender Policy Council. The Initiative aims to recognize and address the historic and persisting gaps in women's health research and, by extension, in our collective knowledge about women's health as well as how women experience certain conditions or respond to certain treatments differently than men. Initiative members include federal agencies, such as the U.S. Departments of Health and Human Services, Defense, and Veterans Affairs, and various White House offices, such as the Office of Management and Budget and the Office of Science and Technology Policy.

Initiative Leaders

The Gender Policy Council (GPC) was established in March of 2021 by President Biden to “advance gender equity and equality in both domestic and foreign policy development and implementation.” The GPC coordinates efforts, programs, and policies related to economic security, gender-based violence, education, health, and equity in leadership, among others. This represents one piece of the Biden Administration's implementation of its National Strategy on Gender Equity and Equality.

First Lady Jill Biden started working on women's health issues in the 1990s when she developed a high school program to teach girls about breast health care. The inspiration for the Initiative reportedly came after First Lady Biden met with women's health advocate and former California first lady Maria Shriver who emphasized the need for efforts to close research gaps in women's health. Carolyn Mazure, Professor at Yale School of Medicine and founder of the Women's Health Research Center, will chair the Initiative.

Need for this Initiative

It was previously assumed that research findings on male participants could be extrapolated to females. In recent years, researchers are recognizing the critical roles that sex (being male or female) and gender identity (including social and cultural factors) play in health, wellness, and disease progression. The Women's Health field has importantly expanded beyond its original

research focus on reproductive health and includes the study of health throughout the lifespan and across the spectrum of scientific investigations.

However, research on conditions that primarily affect women or impact women differently than men have long been underfunded and, as noted by Biden at the time of the Initiative's launch, "these gaps are even greater for communities that have historically been excluded from research, including women of color and women with disabilities." In 2020, only 10.8% of funding from the National Institutes of Health (NIH) went towards women's health research, even when including conditions specific to women and those that predominantly affect women. Researchers found that diseases that predominantly affect women - such as migraines, headaches, anorexia and endometriosis - received funding that was a fraction of what was allocated for diseases that predominantly affect men.

Historically, the NIH and the Food and Drug Administration (FDA) excluded many women from clinical research studies due to concerns over harms to their future potential children. As a result of the under-representation of women in clinical trials, studies have found greater risks of adverse reactions to drugs among women and an increased chance of misdiagnosis of heart attacks among women due to different presentations of symptoms compared to men. Although the agencies now require the participation of women in research, women still make up less than 35% of participants in early-phase clinical trials sponsored by the pharmaceutical industry. Women are not necessarily included in proportions that match the prevalence or burden of disease. For instance, in the United States, although 51% of cancer patients are female, only 41% of cancer trial patients are female. Likewise, almost two-thirds of the 6.2 million people suffering with Alzheimer's are women, but in most animal studies of the disease, researchers haven't reported the sex of the animal they're studying.

These unrepresentative studies have led to a lack of data on women's health, which has adversely impacted providers' abilities to diagnose and treat female patients. For example, an estimated 90% of women with sleep apnea remain undiagnosed because their symptoms differ from those of men and may not be considered "textbook" symptoms. The Initiative aims to drive innovation to redress the many unmet medical needs of women and those assigned female at birth.

Next Steps

The White House directed Initiative members to provide recommendations to advance women's health research within 45 days, making them due at the end of December 2023. After considering the recommendations, the Initiative will identify priority areas for additional investments. Such focus areas could include research on heart attacks in women and menopause.

The White House also plans to engage the private sector, scientific community, and philanthropic leaders in the Initiative's work.

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