

2021

WOMEN'S HEALTH POLICY AGENDA



Society for
Women's Health Research



March 2021

To our supporters and all women's health champions —

As we begin 2021 and mark the start of the 117th Congress, there are more women — on both sides of the aisle — representing our country than ever before, with greater diversity than we have seen in the past. New Mexico is the first state to elect all women of color to the U.S. House of Representatives, and Rep. Yvette Herrell is the first Republican Native American woman in Congress.

Importantly, Vice President Kamala Harris, the daughter of an Indian mother and a Jamaican father, has made history as the first woman and the first woman of color to be elected as vice president in the United States. Vice President Harris has a long track record in the Senate as an advocate for women and women's health.

The Society for Women's Health Research (SWHR) is ready to make the most of the opportunity we have before us. SWHR is a 30-year-old national nonprofit dedicated to promoting research on biological sex and gender differences in disease, and to improving women's health through science, policy, and education. For decades, patients within our health care system who identified as women were simply treated as small men. Research on diseases and treatments was conducted almost exclusively on male subjects, as researchers avoided the presumed "complications" that would be introduced by including two sexes in studies.

Unfortunately, this approach ignores the impact of both sex and gender on our health. Biological differences between women and men influence disease development, progression, and response to treatment, while social determinants of health — including gender — affect disease risk, health care access, and outcomes. Despite the progress that has been made in women's health since SWHR was first founded in 1990, we have much to accomplish in order to ensure the optimal health of all women nationwide.

With this in mind, SWHR is pleased to launch our annual Women's Health Policy Agenda. We believe now is the time to propel women's health forward in five key areas: public health, research & clinical trials, lifespan issues, coverage & access, and the biomedical workforce.

SWHR is also committed to improving health equity through our work. We hope to use our first annual policy agenda as a road map to advance health and wellbeing for all women in 2021 and beyond.

These areas represent crucial components for a revolution in women's health. We can help women to feel more prepared for the physical and behavioral health challenges they may face across the course of their lives. We can drive improved inclusion of women in the science and policy arenas. We can empower women to take charge of their health care.

SWHR invites you to join us in our vision of making women's health mainstream. We can't wait to get started.

Sincerely,

Kathryn G. Schubert, MPP
SWHR President & CEO

"Sex" refers to the biological classification of living things according to reproductive organs and chromosomes. "Gender" refers to an individual's self-identification as masculine, feminine, both, or neither, and is intrinsically associated with sociodemographic factors that ultimately affect health. Both sex and gender influence health across the lifespan, and SWHR strives to comprehensively address both sex and gender as they relate to women's health. When citing research, SWHR uses terminology consistent with what is used in the study. As inclusive language practices continue to evolve in the scientific and medical communities, we will reassess our language as necessary.



The COVID-19 pandemic, which arrived in the U.S. in early 2020, is a stark reminder about the importance of public health and of ensuring women’s unique health needs are appropriately considered in this broader context. Population-level measures — including public health surveillance, data collection, and infrastructure building — are essential building blocks to improving individual health. Below, we highlight key areas of need for women in 2021.



Alzheimer’s Disease

Of the 5.8 million American adults diagnosed with Alzheimer’s disease, about two-thirds are women. Scientists have often overlooked sex and gender differences in Alzheimer’s disease diagnosis, clinical trial design, treatment outcomes, and caregiving, hindering progress in detection and care. SWHR supports increasing research into sex and gender differences in Alzheimer’s disease in order to improve prevention, diagnosis, and treatment for both women and men.



Behavioral Health

Certain mental and behavioral health disorders, such as depression, anxiety, and body image disorders, are more frequently diagnosed in women. Other mental health conditions are specifically linked to the female reproductive cycle and related hormonal changes, including perinatal depression, premenstrual dysphoric disorder, and perimenopause-specific depression. Over 20% of women in the U.S. have experienced a mental health condition in the past year. SWHR supports mental health policies that take into account the specific needs and experiences of women across the lifespan.



Cancer

Certain cancers are more likely to affect women, and many of these cancers are in dire need of innovation in diagnostics and treatments. For example, technology used for screening and diagnosis of ovarian cancer is out-of-date and often fails to catch cancer in its earliest, most curable stages. Other cancers, including many gynecological cancers, carry stigma for patients that can impact diagnosis and care. SWHR supports policies that address gaps in women’s cancer care to reduce cancer mortality, which is the second leading cause of death for women in the U.S.



COVID-19 and Pandemic Preparedness

COVID-19 appears to be infecting similar numbers of women and men. However, the majority of people dying are men, while women are more likely to suffer long-term side effects. Women are also disproportionately affected by layoffs and socioeconomic challenges, food insecurity, domestic violence, and mental health concerns related to COVID-19. SWHR supports policies that account for disparities related to both sex and gender in efforts to curb the ongoing pandemic and in planning for the possibility of future pandemics.



Health Equity

Disparities in access to care and health outcomes across the U.S. persist — and in many cases are worsening. Health disparities refer to differences in health or health care that are tied to social, economic, or environmental status. The presence of disparities does not just affect one community or group of individuals, but broadly impacts population health. SWHR believes sex and gender, race and ethnicity, identity, faith, disability status, pregnancy, socioeconomic status, incarceration, and immigration status should not impede an individual's ability to access or receive quality health care.



Heart Disease

Heart disease has long been portrayed as a man's disease, in part due to the historical underrepresentation of women in medical research examining cardiovascular illness. In reality, heart disease is the number one killer of women nationally, although only about half of women are aware of this fact. SWHR supports improving education and awareness as well as prevention, diagnostic, and treatment methods for women managing cardiovascular disease to reduce mortality in this area.



Immunization

Immunization is a core component of preventative care, and there are clear sex and gender differences in infectious disease risk, response, and prevention. In addition, women are frequently the medical decision-makers for their families and manage the care for their loved ones. As such, SWHR supports vaccine education and promotion efforts that target the needs of women and take into the account the concerns of communities of color as well as individuals who are pregnant.



Maternal Health

Maternal mortality rates in the United States are higher than anywhere in the developed world, and the majority of pregnancy-related deaths are preventable. This is especially true for Black women, as biases in care have led to stark racial disparities in maternal deaths. SWHR supports efforts to increase access to maternity care in rural and underserved areas, help maternity providers and hospitals implement best practices, extend Medicaid coverage for women to one year postpartum, improve maternal morbidity and mortality data collection, support the expansion of perinatal quality collaboratives, and eliminate racial and ethnic inequities.



Violence Prevention

In the wake of a global pandemic, there have been significant increases in reports of intimate partner violence. Funding for mental and behavioral health support for survivors of domestic violence is needed, in addition to housing resources, paid sick time, and protections for immigrants, who may face particular challenges due to concerns about citizenship status and deportation. SWHR supports reauthorization of the Violence Against Women Act, which provides funding to rape crisis centers, shelters, and legal services for survivors.



SWHR supports policies that:

- Adequately fund the public health infrastructure and surveillance systems in the United States.
- Take into account public health needs that may vary based on sex and/or gender.
- Support data collection and surveillance efforts geared toward improving health equity and reducing health disparities.
- Work to eliminate systemic biases within our public health infrastructure and health care system.

The federal government must support research that addresses the unique health needs of women across the lifespan. SWHR urges continued robust funding for federal agencies that support women's health research, as well as federal offices specifically designed to support research on minority health, women's health, and sex as a biological variable.

Federal agencies should seek to fund research that prioritizes understanding and eliminating sex and gender health disparities. Increased investment must be made in areas where there are identified knowledge and funding gaps — for example, the disproportionately low levels of funding for women's health disorders like endometriosis and uterine fibroids. Women's health must be a firm priority for legislators, and this should be reflected through robust funding of women's health research at the federal level.



Preclinical Research

Basic science research must account for sex as a biological variable (SABV) to better understand its impact on health. SWHR supports studying, analyzing, and reporting on biological sex differences as standard practice. Exceptions should only occur in scientifically justified cases, such as when a study focuses on a sex-specific condition or prior evidence suggests no sex differences exist.



Clinical Trials

Clinical research participants must be representative of the patient population being studied. Despite improvements in clinical trials diversity, work remains to be done, especially with regard to the participation of African Americans. In 2018, over 52% of participants in NIH-supported clinical research were women, while about 29% were members of racial minority groups and 9% were ethnic minorities.



Pregnancy and Lactation

The exclusion of pregnant and lactating people in research has led to significant, unacceptable knowledge gaps that hinder clinical decision-making and may harm health. SWHR strongly supports appropriate inclusion of pregnant and lactating individuals in clinical studies to protect them through research, not from research. SWHR urges the implementation of all 15 recommendations developed by the federal Task Force on Research Specific to Pregnant Women and Lactating Women (PRGLAC) aimed at improving the development of safe and effective therapies for these populations.



SWHR supports policies that:

- Require the inclusion of women — including pregnant and lactating individuals — and underrepresented groups in research in numbers proportionate to their prevalence in the patient population of the disease being studied.
- Expand the exploration of SABV and improve training of researchers on SABV study design, analysis, and reporting for preclinical and clinical research.
- Improve training for grant reviewers to ensure regulations related to sex and gender are properly incorporated within proposals submitted to federal agencies.
- Create incentives to add a sex and/or gender component to existing research programs.
- Require researchers to use study designs that allow for sufficient analytical power to return statistically significant outcomes within sex- or gender-disaggregated analyses, and further, to publish outcome data from these analyses.
- Expand oversight of NIH policy that mandates consideration of SABV in preclinical research and harmonize these recommendations across federal agencies funding or providing oversight of preclinical studies.

Discussions about women's health are often focused on reproductive issues, yet this stage of a woman's life lasts, on average, about 36 years, whereas the average life expectancy for women in the U.S. is closer to 80 years. Women live over half of their lives in pre- or post-reproductive life stages, and their health needs encompass more than pregnancy and reproductive care. Policy must consider the needs of all women in all stages of life, while striving to eliminate health disparities that persist both between and within genders.



Early Adulthood

During this time, women's care should address sexual and reproductive needs and include screening for physical and behavioral conditions. Some young women may not have a regular primary care provider, and many will rely on their OB-GYN as their primary physician. Some individuals may begin to experience chronic health conditions in early adulthood like endometriosis, fibroids, or migraine. Mental health issues are of particular concern as almost a third of women struggle with anxiety or depression in their 20s. Intimate partner violence is more common during the young adult years, although this problem does not disappear later in life.



Middle Adulthood

Reported health begins to decline as women age. Perimenopause typically begins during a woman's 40s, and menopause usually occurs in a woman's early 50s. The hormonal changes associated with this transition affect many aspects of an individual's life. Disability and physical limitations and chronic conditions also become more prevalent during this time. Screening for chronic disease and cancer is of the utmost importance at this stage in life. Issues such as bone health and chronic pain become more pressing. In addition, women increasingly become caregivers as they age, so attention to issues affecting caregivers — mental health, stress-related symptoms, and higher rates of chronic conditions — is important.



Late Adulthood

Elderly women have the highest prevalence of activity-limiting health conditions as compared to other age groups. Depression and anxiety are also more likely to go unrecognized or underrecognized, and cognitive issues like dementia become notable. For example, more women than men are diagnosed with Alzheimer's disease. Elderly women are also least likely to exercise. Over 80% of women in this age range have had contact with a health care provider in the past six months, so insurance issues like gaps in Medicare coverage become critical barriers to health care.



SWHR supports policies that:

- Address women's health across the lifespan.
- Promote preventative care for women as a means of improving long-term health and quality of life.
- Consider how events that occur early in life may impact a woman's health as they age.
- Support women receiving personalized care, tailored to their individual life stage and experiences.
- Remove barriers to access and affordability, which evolve over the course of the lifespan.

Women are less likely than men to be uninsured following implementation of the Affordable Care Act. From 2013 to 2017, the uninsured rate among women fell from 18% of 12% nationally.

However, women also face barriers to care that men typically do not. Women are more likely to earn less than men, they tend to use health care services at higher rates, and they are more likely to be caregivers for older, sicker family members.



Affordability

More women than men — 26% versus 19% — have had to go without care or delay care due to high out-of-pocket costs. In the previous year, one in every five women has delayed preventive care, skipped recommended services, or not filled their medication or skipped medication dosages due to cost concerns. Treatment must be affordable for all, and sex and gender should be considered when conducting value assessment for new therapeutics.



Medicaid

Medicaid covers 16.5% of women under the age of 65 years, and approximately two-thirds of women on Medicaid are of childbearing age (19–49 years). Perhaps even more significantly, Medicaid covers almost half of births in the U.S. and provides three-quarters of publicly-funded family planning services. Medicaid also covers over a third of nonelderly women with disabilities, and women represent 60% of Medicaid's "dual eligible" beneficiaries, who qualify for both Medicaid and Medicare simultaneously.



Medicare

Women have longer life expectancies than men and represent almost 60% of individuals covered by Medicare. Older women are at higher risk for a multitude of health issues, including osteoarthritis and bone health concerns, Alzheimer's disease, and bladder issues. Women are also more likely than men to be widowed and live alone as they age, and they tend to have lower incomes toward the end of their lives because of the higher amounts of time spent outside of the workforce caring for family members.



SWHR supports policies that:

- Control out-of-pocket costs for women while ensuring uninterrupted access to all essential health benefits as outlined in the ACA.
- Take into account the unique needs of women as family leaders, decision-makers, and primary caregivers.
- Strengthen protections for women and improve access to care under public and private insurance programs, while guarding against cuts in service, eligibility, or access to needed therapies.
- Ensure value frameworks are appropriately designed and used to provide reasonable, affordable access to innovative new therapies and interventions for women.
- Ensure equitable affordability and access.
- Prioritize mental and behavioral health, as well as mental and behavioral health parity.
- Continue COVID-19 expansions in access to telehealth services on a permanent basis.
- Expand Medicaid coverage for pregnant individuals to one-year postpartum.



Diversity makes science better. Data suggest that gender diversity may broaden the viewpoints, questions, and areas explored by researchers, allowing greater potential for new discoveries. Without women and other underrepresented groups in science, the world may miss out on valuable innovations and ideas that alternate perspectives bring to the table.

SWHR supports efforts that improve the representation of women and other historically underrepresented groups within all levels of the biomedical workforce.



The Gender Problem in the Biomedical Workforce

Women are broadly underrepresented in science, technology, engineering, and math (STEM) careers. While these are some of the most rapidly growing job paths in the U.S., women represent only a quarter of those employed within these fields.

Additionally, research shows that women researchers typically earn less, receive less funding at the beginning of their careers, and are cited less often than their male counterparts. In addition, women researchers are much more likely to switch to part-time work, change career paths, or leave the workforce entirely compared to men. For example, one study showed new mothers are much more likely to leave full-time STEM jobs than new fathers after the birth or adoption of their first child.

Women in the biomedical workforce also disproportionately face sexual harassment and discrimination. According to a survey of women in science-related jobs, 91% said gender discrimination remains a career obstacle and 73% said sexual harassment was as an obstacle to women's career trajectories in the postdoctoral stage.

Individuals of all genders, races and ethnicities, socioeconomic circumstances, and other diverse backgrounds deserve a safe, supportive, and discrimination-free workplace and the opportunity to succeed within their careers.

COVID-19 is exacerbating pre-existing challenges facing women and people of color in STEM careers, leading to decreased productivity and loss of women in the workforce. SWHR strongly believes policies supporting the research workforce and infrastructure during the pandemic must include specific mention of populations disproportionately impacted, including women. Strategies to mitigate harm should prioritize addressing the needs of these populations most urgently.



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SWHR supports policies that:

- Improve representation of women and other historically underrepresented groups
- Increase efforts to recruit and retain women and underrepresented groups
- Help women and members of underrepresented groups advance to leadership roles
- Reduce the burden of sexism, racism, and other forms of prejudice or institutional bias
- Remove systemic barriers that broadly impede the advancement of women
- Foster safe work environments by addressing sexual harassment concerns and implementing strong sanctions against those found guilty of harassment.