

2022

WOMEN'S HEALTH POLICY AGENDA



March 2022

To our supporters and all women's health champions —

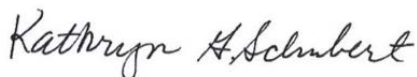
As we collectively continue to deal with COVID-19 and its aftermath, we at the Society for Women's Health Research (SWHR) have reflected on what the pandemic means for our nation's public health. Most importantly, we were reminded of the importance of our nation's science research agencies and public health infrastructure. But notably, we were also reminded of the importance of considering women's unique health needs in the broader context of public health, as issues—such as whether a vaccine is safe and effective for pregnant and lactating populations, how insurance affects one's ability to receive a COVID-19 test, or how caregiving impacts one's physical and mental health—came to light.

We know that women face unique challenges over the course of their lifespans. Whether considering female underrepresentation in research; the role of women as caregiver and chief family medical decision-maker; barriers to care, such as cost, access issues, or discriminatory practices; or biological sex differences that contribute to disease burden, women continue to represent an important opportunity for the U.S. health care system and for the policy community to ensure systems and policies reflect women getting what they need.

As we enter 2022, SWHR is pleased to introduce the second annual Women's Health Policy Agenda. There is tremendous opportunity before us to propel women's health forward and close critical gaps. We hope that this agenda—building off of our 2021 Agenda and covering public health, research and clinical trials, lifespan issues, coverage and access, and the biomedical research workforce—will continue to serve as a roadmap to advance the health and well-being for all women in 2022 and beyond.

We invite you to join us in our vision of making women's health mainstream and look forward to collaborating this year and in years to come.

Sincerely,



Kathryn G. Schubert, MPP
President & CEO
Society for Women's Health Research

"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.



Public health is defined as “science of protecting and improving the health of people and their communities.” Public health is preventive in nature; it aims to prevent problems through education, policy, and research, rather than on treatment after an issue arises. SWHR believes that public health measures—such as education and awareness, preventive measures, public health surveillance, data collection, and shoring up the nation’s research infrastructure and capacity—are all essential to improving individual and population health.

As the United States grapples with the lingering COVID-19 crisis and examines and implements lessons learned, it will be important to revitalize broader efforts to prevent disease, promote health, and respond to emerging situations and challenges. Below, SWHR highlights some key areas of need for women in 2022.



Alzheimer’s Disease*

Of the more than 6 million Americans age 65 and older in the United States, almost two-thirds are women. According to statistics from the Alzheimer’s Association, women in their 60s are more than twice as likely to develop Alzheimer’s disease over the rest of their lives as they are to develop breast cancer. 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.



Autoimmune Diseases and Conditions

NEW IN 2022

Autoimmune diseases, which cause a person’s immune system to attack the body’s own tissues and organs, have a greater prevalence among women than men. More than 100 types of autoimmune diseases predominately affect women, and women comprise nearly 80% of the population affected by autoimmune diseases. Some of these disorders are genetic, whereas others may affect women during periods of stress, such as pregnancy or during great hormonal changes. With autoimmune diseases on the rise worldwide, and given that women bear a disproportionate burden of the high morbidity associated with these conditions, SWHR supports additional research into the development of new treatments to prevent and treat autoimmune conditions.



Behavioral Health

While mental illnesses are common in the United States (approximately 52.9 million adults lived with a mental illness in 2020), many mental and behavioral health disorders are more prevalent in women or may affect women in different ways than they affect men. Some 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, but other personal circumstances and experiences are also associated with a higher risk of depression. As of 2019, more than 1 in 5 U.S. women experienced a mental health condition in the past year. Now, in light of the COVID-19 pandemic, which has resulted in “alarmingly high rates of mental health problems” among women, SWHR supports policies that take into account the specific needs and experiences of women across the lifespan and encourages additional research into the biological and physiological factors that could affect the mental health of both men and women.



Bone Health*

NEW IN 2022

Each year, an estimated 1.5 million individuals suffer a fracture due to bone disease. The risk of a fracture increases with age and is greatest in women. Women also account for 80% of the estimated 10 million Americans with osteoporosis, the most common form of bone disease. Nearly 1 in 5 Medicare beneficiaries have died from complications within 12 months after an osteoporotic fracture—and more than 60% were women. SWHR encourages policies that promote access to affordable, high-quality bone health screening, access to effective therapies, research into the preservation and treatment of bone, and education about how to prevent fractures and improve health outcomes.



Cancer

Cancer is the second leading cause of death for women in the United States. Some cancers, like gynecological cancers, are exclusive to women; others, like anal cancer, are more likely to occur in women. In order to improve health outcomes across different types of cancer, SWHR supports providing funding to create novel diagnostics and treatments that incorporate women's preferences; improving education for and removing the stigma around certain gynecologic cancers; improving access to cancer screening and testing; and creating screening guidelines across different types of cancer.



Diagnostic Testing

NEW IN 2022

Men and women are likely to need diagnostic services (screenings and tests to help diseases or conditions) at some point in their lives. Women may require these services related to diseases and conditions common to both sexes as well as for conditions unique to women (e.g., mammograms and tests related to pregnancy). Diagnostic services are important for diagnosis and monitoring and can be useful tools for helping women make informed decisions about their reproductive health and pregnancy management, and may improve maternal and fetal outcomes by allowing preparation to care for children who may have a genetic disorder. SWHR supports policies that remove barriers to understanding and accessing screening options and genetic counseling.



Health Equity

Disparities in access to care and health outcomes across the United States 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; it impacts population health. Health equity cannot exist until knowledge gaps in women's research are closed, until women receive equal access to care, and until women's health is mainstream. SWHR believes that 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.



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.



Heart Disease

Heart disease is the number one killer of women nationally, causing about 1 in every 5 female deaths, and is one of the most preventable diseases. Yet, many women do not recognize heart disease as their greatest health risk, and research and clinical care gaps remain. SWHR supports improving education and awareness among clinicians and the public as well as funding research into sex differences in heart disease that could help improve prevention, diagnosis, and treatment in women in order to reduce mortality.



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 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 account the concerns of communities of color as well as individuals who are pregnant.



Long COVID

NEW IN 2022

Long COVID—which involves new, returning, or ongoing health problems people may experience more than four weeks after being first infected with SARS-CoV-2—affects roughly 10% of those infected with COVID-19. Yet, early reports indicate that long COVID is diagnosed more frequently in women than in men. Some studies have shown differences in symptoms, such as fatigue, but the reason behind the association is unclear. Researchers suggest that differences with ethnicity, socioeconomic status, immune response, or hormones could all serve as possible explanations for the contrasting results. SWHR supports additional research into long COVID, including sex and gender disparities on the condition, as well as research into long COVID's effect on quality of life.



Maternal Health

Maternal mortality rates in the United States are higher than anywhere in the developed world, with widening disparities in outcomes for Black, Indigenous, People of Color (BIPOC). The majority of pregnancy-related deaths are preventable. SWHR continues to champion efforts to increase access to maternity care in rural and underserved areas, help maternity care 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.



Menopause

NEW IN 2022

Approximately 1.3 million women transition into menopause each year. The menopausal transition most often begins between ages 45 and 55, intersecting with a critical career stage, and can be accompanied by symptoms, including vasomotor symptoms (hot flashes and night sweats), depression, and sleep disturbances. SWHR supports continued efforts to raise awareness about menopause as well as policies that improve access and insurance coverage for menopause treatments; address ageism and protect women in the workplace; and provide better access to programs and facilities that allow women to adopt healthier lifestyles as they age.



Women as Caregivers

NEW IN 2022

According to the Institute on Aging, upwards of 75 percent of all caregivers are women, and female caregivers may spend as much as 50% or more time providing care than men. Women who are caregivers are at greater risk for poor physical and mental health, including depression and anxiety. These stressors were exacerbated, and caregiving responsibilities increased, for many women during the COVID-19 pandemic. SWHR encourages exploring structural policy change that would support women caregivers, including those that improve workplace flexibility and increase resources for child care providers.

** Indicates issue-specific policy agenda forthcoming.*

The federal government must support research that addresses the unique health needs of women across the lifespan. SWHR urges robust funding for federal agencies that conduct women's health research as well as funding, programs, and initiatives that support research on minority health, women's health, and sex as a biological variable (SABV).

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, such as endometriosis and uterine fibroids. Women's health must be a priority for legislators, reflected through sufficient federal research funding and policies that support, and do not unnecessarily restrict, advances in women's health.



Accounting for Sex in Research

Basic science research must account for 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.



Appropriate Inclusion of Pregnant and Lactating Populations

The exclusion of pregnant and lactating people in research has led to significant knowledge gaps that hinder clinical decision-making and may harm health. This came to light during the COVID-19 pandemic, when there was a significant delay in getting pregnant people included in the vaccine trials. Due in part to poorly justified concerns about the safety of medications and vaccines during pregnancy, these families missed an important health prevention opportunity, and many have suffered as a result. SWHR strongly supports the 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 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 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.





Diversity in Clinical Trials

Clinical research participants must be representative of the patient population to reduce disparities and achieve equity. Despite improvements in clinical trial diversity, work remains, particularly in having minority racial and ethnic groups represented. In fiscal year 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. Similarly, 75% of the 32,000 participants in the trials of 53 novel drugs approved in 2020 by the FDA were white. SWHR urges the prioritization of enhancing clinical trial diversity by removing barriers to trial participation, improving the diversity of the research workforce, and establishing policies that create accountability.



Ensuring Women's Health Conditions are Accounted for in Research

NEW IN 2022

In order to understand and respond to the life stages, diseases, and conditions that differently, disproportionately, or exclusively affect women, data need to capture elements related to women's health. As one example, the NIH's Research, Condition, and Disease Categorization (RCDC), which is used to categorize the agency's funding in medical research at the end of each fiscal year, currently does not include a code for menopause, a vital life stage with critical health implications that affects all women. SWHR encourages ensuring policies reflect women's unique health needs in federal research policies.



Securing Sufficient Federal Funding for Women's Health Research

NEW IN 2022

America's federal research agencies are vital to the health and wellness of all Americans. Ensuring these research entities—including but not limited to the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Centers for Medicare and Medicaid Services (CMS), and the Agency for Healthcare Research and Quality (AHRQ)—have sufficient federal funding and the capacity to carry out their respective missions is critical for improving our knowledge base and driving progress forward. Especially in the wake of the COVID-19 pandemic, which disproportionately impacted early career researchers, women, and underrepresented minorities, it is vital that these agencies receive robust annual funding increases to correct course following the pandemic as well as to maximize the potential of these agencies for the good of the American people.

Discussions about women's health are often focused on reproductive years; yet, women live over half of their lives in the pre- or post-reproductive life stages (the reproductive stage of a woman's life lasts, on average, about 36 years, whereas the average life expectancy for women in the United States is closer to 80 years). Policy must view women's health across the lifespan, considering the needs of women in each stage of life, while also striving to eliminate health disparities that persist both within populations of women and between women and men.



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, and issues such as bone health and chronic pain become more pressing. Screening for chronic disease and cancer is of the utmost importance at this stage in life. In addition, women increasingly become caregivers as they age, so attention to issues affecting caregivers—including 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. Further, women ages 65 and older face unique challenges to sustaining good health, including economic insecurity, health care costs, and greater functional impairments.



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.
- Create interoperable health technologies and platforms that capture health data across the lifespan.
- 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 to be uninsured than men. In 2020, approximately 11% of women ages 19-64 were uninsured, compared to approximately 13% of men. Uninsured women often have inadequate access to care and have poorer health outcomes.

Yet, women face unique challenges and barriers to care. Gaps in medical training, rising out-of-pocket costs, access barriers, and underrepresentation of women in health care leaders can all inhibit the health care system from meeting the needs of women across the lifespan.



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, 1 in every 5 women had 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

As of 2019, adult women comprised 36% of the overall Medicaid population and the majority of adults on the program. Approximately two-thirds of women on Medicaid are in their reproductive years (19–49). Perhaps even more significantly, Medicaid is the largest single payer of pregnancy-related services, financing 42% of all U.S. births in 2019. Medicaid also covers 44% of nonelderly women with disabilities.



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.



Value Frameworks and Assessments

NEW IN 2022

Value assessment frameworks have emerged to help different stakeholders, such as clinicians and payers, make health care decisions based on clinical and economic evidence. However, there are important health equity considerations when it comes to defining and measuring value. SWHR encourages the incorporation of diverse perspectives to better understand the value of health equity in these frameworks and is committed to ensuring they are appropriately designed and used to provide appropriate access to new therapies and interventions to achieve optimal health outcomes for women as patients, caregivers, and health care decision-makers for themselves and their families.



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.



Society for
Women's Health Research

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 diverse 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

Although women account for about half of medical graduates and doctoral recipients in the biological sciences, they are underrepresented at all levels of leadership in the biomedical field. Despite science, technology, engineering, and math (STEM) careers being some of the most rapidly growing job paths in the United States, women represented only 27% of those employed within these fields in 2019.

Further, research shows that women in research often earn less, receive less funding at the beginning of their careers, and are cited less frequently than their male counterparts. Women are also more likely to switch to part-time work, change careers, or leave the workforce.

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. Disparities are even greater for women of color, who encounter both significant racial and gender biases. These biases can present differently, but have a detrimental impact on those forced to confront them. For example, Black women are significantly more likely to report having to provide more evidence of competence to prove themselves to colleagues, and Latinas are more frequently perceived as "angry" or "emotional." Black women are also more likely to report feeling isolated in their work environment.

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.

Emerging evidence reveals that COVID-19 is exacerbating pre-existing challenges facing women and people of color in STEM careers, leading to decreased productivity, issues with work-life boundary control, and mental well-being. Emerging data also show that there could be issues retaining 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.



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.