

ALIGNING RESEARCH, POLICY, AND PRACTICE TO TRANSFORM PCOS CARE

A Call to Action from the Society for Women's Health Research



BACKGROUND

Polycystic ovary syndrome (PCOS) is a complex hormonal disorder that affects an estimated 5 million women in the United States, making it one of the most common endocrine disorders among women of reproductive age.¹ PCOS is characterized by elevated androgen levels, which disrupt ovulation and make it one of the leading causes of anovulatory infertility. The etiology of this syndrome remains unknown, and its symptoms, which include irregular menstruation, acne, weight gain, and hirsutism (excessive male-patterned hair growth in women), vary widely in presentation and severity. Underlying much of the pathophysiology of PCOS is insulin resistance, which not only contributes to its hallmark symptoms but also places individuals at higher risk for long-term health complications such as type 2 diabetes, heart disease, and stroke.² Women living with PCOS are also at elevated risk for anxiety, depression, and endometrial cancer.

PCOS remains significantly underdiagnosed, with nearly 70% of women living with PCOS unaware of their condition.¹ In the United States, current diagnostic criteria are inconsistently applied and often poorly understood by providers and patients alike – only 55% of OB-GYN residents recognize the three Rotterdam criteria for PCOS diagnosis and over one-third of patients wait more than two years for an accurate diagnosis.³

The economic burden of PCOS in the United States is estimated at \$8-15 billion.^{4,5} Individuals living with PCOS often face disproportionately high out-of-pocket costs for managing symptoms, pursuing fertility treatments, and addressing the long-term complications associated with PCOS. Moreover, there are no available FDA-approved medications to specifically treat PCOS.⁶ Providers must rely on off-label treatments, many of which fail to address the full spectrum. Studies continue to document patients experiencing limited access to referrals for nutrition and behavioral health services.⁷ In the absence of comprehensive and accessible provider guidance, patients are increasingly turning to social media for their health care information and engagement. Misinformation and content written by non-experts threaten the accuracy and safety of online content for patients with PCOS.

CALL TO ACTION

Recognizing the need to address this critical women's health issue, the Society for Women's Health Research (SWHR) emphasizes the following priority areas to close persistent gaps in PCOS research, education, and advocacy and to improve health outcomes for women:

- > **Invest in research and development of diagnostic innovations for PCOS.** Limited understanding of PCOS physiology and poorly understood diagnostic criteria contribute to delays in care and heightened emotional, physical, and economic burden. Research investments should support the development of precise, accessible diagnostic tools that reflect the multifactorial nature of PCOS, including innovations in hormone panel analysis, androgen detection, epigenetic profiling, and the application of artificial intelligence

to imaging and symptom data. These technologies hold promise in reducing time and enhancing the accuracy of PCOS diagnoses. Investment should be prioritized to maximize impact across public-private partnerships by engaging industry stakeholders and funders who can accelerate innovation and expand access to tools.

- **Strengthen interdisciplinary health care coordination for patients.** While PCOS is often diagnosed due to menstrual irregularities or fertility challenges, the condition extends far beyond ovulation. Women with this chronic condition routinely navigate between gynecologists, endocrinologists, dermatologists, and mental health professionals, with limited support for coordinated or continuous care across disciplines throughout their lives. PCOS care must be reframed as a whole-body condition that demands interdisciplinary collaboration and long-term management that spans mental health screening and preconception counseling to cardiovascular risk assessment. PCOS and insulin resistance awareness should be integrated into clinical education and care across diverse settings and specialties, including primary care, pediatrics, adolescent medicine, and mental health.
- **Expand coverage to ensure holistic PCOS care.** Coverage should be available for holistic PCOS care that addresses both the condition itself and its comorbidities. This would include management of hirsutism and hair loss, acne, metabolic health, nutrition, infertility, cardiovascular disease, and pre-diabetes. Policy solutions must mitigate financial barriers, particularly for uninsured and underinsured populations, and create affordable care pathways that can ensure patients receive timely and comprehensive treatment. Policymakers must take action to address critical gaps in access to and affordability of PCOS care.
- **Increase awareness around PCOS symptoms and whole-body health impacts.** PCOS education is often limited to fertility care and hyper-focused on weight loss, leaving patients with little guidance on its broader impacts on women's health, including insulin resistance, gastrointestinal issues, and mental health symptoms. This lack of holistic and accessible education can undermine an individual's ability to advocate for the appropriate care needed to address the lifelong challenges associated with PCOS. Researchers and health care providers must partner to establish trustworthy, accurate, and culturally appropriate educational tools that empower informed decision-making for women living with PCOS.

Through a series of meetings held with the SWHR PCOS Working Group of interdisciplinary experts across PCOS and women's health, several approaches were highlighted to improve health care and quality of life outcomes for women living with PCOS. SWHR proposes that the above key actions in PCOS research, education, and health care are imperative to reducing the economic and disease burden of PCOS across the lifespan. SWHR looks forward to collaborating with colleagues across the research, health care, and advocacy communities to advance these recommendations and create lasting change for women and communities affected by PCOS.

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