News and Perspectives

The Phendo Project: How FemTech Is Advancing Endometriosis Research and Women's Health

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Abstract

FemTech continues to evolve and advance despite persistent research and funding gaps. In this *News and Perspectives* article, JMIR Correspondent Jenny Castillo Cato reports on an innovative, cross-disciplinary research project targeting endometriosis and implications for the broader FemTech movement.

Key Takeaways:

- Research generated through the free mobile app Phendo is helping advance our understanding of endometriosis and improve patient care.
- By combining FemTech innovation and academic medical research, we can accelerate progress in women's reproductive health.

In this article, Jenny Castillo Cato, MD, a board-certified emergency medicine physician, continues her series on FemTech. She highlights endometriosis as a case study, speaking with Noémie Elhadad, PhD, about her team's initiatives to advance endometriosis research and care.

In 1845, Dr James Marion Sims was celebrated as a pioneer after developing a doubly bent spoon-like instrument to retract the vaginal walls during surgery. He tested and refined this device by operating on enslaved women without anesthesia. This device, used in some of the most intimate and important aspects of women's health care, has undergone little meaningful redesign in more than 150 years.

This example underscores a longstanding lack of research and innovation devoted to women's health, something the FemTech movement—and researchers like Noémie Elhadad, PhD—are working to change.

I spoke with Elhadad, Associate Professor and Chair of Biomedical Informatics, Vice Dean for AI Initiatives at the Columbia University Vagelos College of Physicians and Surgeons, about her research and innovation advancing care for endometriosis, a historically underfunded women's health issue.

The Phendo App

Endometriosis, a systemic disease that extends beyond the reproductive system, affects an estimated 200 million women worldwide, yet remains difficult to diagnose. Currently, the only definitive method of diagnosing endometriosis is through laparoscopic surgery with pathological confirmation. There are no validated blood tests or noninvasive imaging modalities—including computed tomography (CT), ultrasound, or magnetic resonance imaging (MRI)—that can reliably confirm the disease. Consequently, the average time from symptom onset to diagnosis is approximately 10 years.

Elhadad's work combines medicine, AI, and human-centered computing to study endometriosis. Recognizing that electronic health records often failed to capture the condition, she shifted her focus directly to the patients experiencing its symptoms, founding the Citizen Endo research project, a collaboration between researchers and patients.

As part of this project, Elhadad has spent the past decade developing Phendo, a free mobile app that enables more than 22,000 users to track symptoms, document self-management strategies, and securely share their health histories with researchers. Researchers access these data in accordance with Health Insurance Portability and Accountability Act (HIPAA) privacy and security requirements, creating a rich, patient-generated dataset.

Through both her research and her own experiences as a patient, Elhadad recognized that many health care providers lack adequate knowledge of endometriosis, resulting in symptoms often being dismissed or minimized, leaving many women feeling misunderstood, invalidated, and even labeled as "crazy."

To address this gap, Phendo was designed not only as a research tool but also as a patient empowerment platform. Users can track symptoms over time and generate downloadable graphs and reports to share with their health care providers. As Elhadad explained, presenting symptom data in a structured, visual format helps patients communicate their experiences more effectively and lends greater credibility to symptoms that have been overlooked.

Overlooked and Underfunded

Despite its prevalence and impact on quality of life, endometriosis research remains significantly underfunded. Elhadad notes that, although she had previously secured federal research grants without difficulty, funding opportunities became scarce after shifting her research focus to endometriosis. And the challenges extended beyond funding.

After collecting extensive patient-generated data, Elhadad also encountered resistance from the scientific publishing community. Some peer-reviewed medical journals questioned the validity of self-reported patient data, arguing that symptom reports based on patients' lived experiences could "not be trusted" and were insufficient without pathological confirmation or objective biomarkers. This skepticism reflected broader methodological debates and concerns within traditional medical research about whether and how patient-reported experiences could be included as valid, reliable scientific evidence. Efforts have since been made to identify and standardize patient-reported outcomes for use in endometriosis care, where definitive diagnostic tools remain limited, but the call to action remains urgent.

Research Gaps

Historically, for decades, women were routinely excluded from clinical research because they were considered too complex or risky to study. It was not until the passage of the National Institutes of Health (NIH) Revitalization Act of 1993 that federally funded clinical research in the United States was required to include women and members of minority groups, helping to address critical gaps in medical knowledge.

Medical journal publication trends further illustrate the disparity in research attention devoted to women's health. A 2020 observational study of the high-impact *British Medical Journal* (BMJ) analyzed articles published between 1948 and 2018 and found that increases in women's health publications have often been temporary and corresponded with major medical advances and public health initiatives rather than reflecting sustained research investment. While publication volume alone is not a direct measure of scientific investment, it serves as a useful indicator of research priorities within academic medicine and underscores the persistent underrepresentation of women's health in the scientific literature.

Additionally, research devoted to women's health continues to receive disproportionately limited financial support. A study evaluating the distribution of the NIH's US $45 billion research budget in 2022 found that conditions that disproportionately affect women—including headaches, endometriosis, and anxiety disorders—received substantially less funding relative to their impact on population health. Comparable disparities have also been documented internationally.

> *For women's health to advance, FemTech and the academic medical research community must work together rather than in parallel, complementing each other's strengths.*

FemTech's emergence—and its evolution into "Deep FemTech," a term introduced by Theresa Neil that describes the shifting focus toward fundamental scientific and engineering advances that go beyond reproductive health—signals a promising avenue for innovation outside of the traditional academic medical setting. The academic research community, much like the investment landscape, however, has been slow to fully embrace this field.

A bibliometric analysis of FemTech research identified only 183 peer-reviewed publications between 2013 and 2023, with more than 80% published during the final 5 years of the study period. The analysis also found that most publications were authored by a single investigator, with limited interdisciplinary collaboration across fields such as medicine, engineering, computer science, and business. This lack of cross-disciplinary engagement represents a significant barrier to innovation. Addressing complex challenges in women's health care requires interdisciplinary collaboration essential to accelerating research, developing novel technologies, and translating innovation into meaningful improvements in clinical care.

Closing the Gap

For women's health to advance, FemTech and the academic medical research community must work together rather than in parallel, complementing each other's strengths.

The technology sector excels at rapid innovation, user-centered design, and scaling solutions to millions of people; however, innovation must be grounded in ethical principles, scientific validity, equitable access, and robust protections for patient privacy and data security. The academic research community, by contrast, provides the scientific rigor, methodological expertise, and peer review necessary to ensure that new technologies are safe, effective, and evidence-based—but could itself benefit from embracing novel sources of patient-generated data and recognizing the value of symptom-tracking, patient-reported outcomes, and digital health platforms as legitimate tools for advancing scientific discovery. Conditions such as endometriosis—and

work such as that by Elhadad and her team—demonstrate the value of this kind of collaborative work for revealing important insights that might otherwise be missed.

As an emergency medicine physician with more than 26 years of clinical experience, I have cared for thousands of women whose symptoms, concerns, and diagnoses have too often been delayed or overlooked. Their experiences underscore the urgent need for innovation that is both scientifically rigorous and patient-centered. I urge leaders in medicine, technology, and government to make women's health a research and innovation priority. Investing in FemTech is an investment in the health and well-being of nearly half of the world's population.

Keywords: endometriosis; women's health; biomedical research; health services research; artificial intelligence; machine learning; AI

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