

AMERICAN MEDICAL ASSOCIATION WOMEN PHYSICIANS SECTION

Resolution 1
(I-23)

Introduced by: Sara Kazyak, Wayne State University School of Medicine; Arelys Hernandez,
Sam Houston College of Osteopathic Medicine

Subject: Addressing Disparities and Lack of Research for Endometriosis

Whereas, Endometriosis is defined as a medical condition in which endometrial-like tissue from the uterus grows in a location outside of the uterus¹; and

Whereas, An estimated 11% of women in the United States have endometriosis, though this was noted to be a conservative estimate, as the actual percentage of patients with this condition would likely increase when considering individuals with symptoms below the clinical threshold or a patient population containing of all individuals with uterus²; and

Whereas, Endometriosis is the third most common cause of gynecological-related hospitalization and when patient populations are stratified by diagnostic indicators, the incidence of endometriosis were found to be as high as 71.4%^{4,3}; and

Whereas, Endometriosis is one of the most common reproductive conditions among women compared to 11% of women of reproductive age experience infertility, 5-10% experiencing Polycystic Ovarian Syndrome (PCOS), and 0.7% experiencing cervical cancer⁵⁻⁷; and

Whereas, Although novel mechanisms contributing to the development of endometriosis have been suggested, there is currently no single, widely accepted etiology for endometriosis⁸⁻¹⁰; and

Whereas, Symptoms of endometriosis vary from asymptomatic to severe pelvic pain, and bleeding, many symptoms of endometriosis can have multiple causes, making endometriosis difficult to diagnose¹¹; and

Whereas, The most common classification system of endometriosis, the revised American Society of Reproductive Medicine (rASRM) classification system, was created in 1968 and considers endometriosis involvement of the peritoneum, fallopian tubes, ovaries, and cul-de-sac, but has been found to have numerous disadvantages, indicating the need for additional research to improve this system^{12,13}; and

Whereas, The length of time for a patient to receive an endometriosis diagnosis appears to have decreased in recent years, a diagnosis of endometriosis typically takes an average of 4-11 years, and the amount of time for diagnosis in Black and Hispanic women is considerably higher^{14,15, 31}; and

Whereas, Multiple studies have suggested that diet may play an important role in alleviating endometriosis symptoms, however, the studies are limited with small sample sizes, which further points to the growing need for additional endometriosis research and awareness¹⁶⁻¹⁸; and

1 Whereas, In the current endometriosis research that does exist, small sample sizes are
2 common, which prevents the creation of evidence-based guidelines for practitioners¹⁶⁻¹⁸; and
3

4 Whereas, Endometriosis has been found to have a significant negative impact on the quality of
5 life of those diagnosed, including increased cost of healthcare, higher healthcare resource
6 utilization, and decreased productivity at both home and workplace¹⁹⁻²¹; and
7

8 Whereas, Black and Hispanic patients are less likely to receive a diagnosis of endometriosis
9 than their White or Asian counterparts, further contributing to a delay in diagnosis and placing a
10 disproportionate healthcare burden on these patients²²; and
11

12 Whereas, The American Journal of Obstetrics and Gynecology has previously noted the
13 prolonged period between presentation of endometriosis symptoms and treatment for or
14 diagnosis of endometriosis, as well as the health disparities this may cause¹⁵; and
15

16 Whereas, A majority of recommendation for practice regarding endometriosis from the American
17 Academy of Family Physicians are based on consensus, expert opinion, and disease-oriented
18 evidence rather than research, indicating the need for additional endometriosis research to
19 improve endometriosis guidelines for physician practice²³; and
20

21 Whereas, The American College of Obstetricians and Gynecologists has multiple practice
22 guidelines based on scientific evidence that outline different combinations of medication and
23 surgical intervention as treatment options for endometriosis, but many are dependent on a prior
24 diagnosis of endometriosis²⁴; and
25

26 Whereas, The American Society of Reproductive Medicine has multiple fact sheets on
27 endometriosis available for patients, but no practice documents for practitioners specifically
28 dedicated to endometriosis²⁵; and
29

30 Whereas, It is clear that additional research is needed to understand symptoms, causes, and
31 treatment of endometriosis, however the National Institute of Health (NIH) dedicates only
32 0.038% of the overall NIH budget to endometriosis research²⁶; and
33

34 Whereas, Endometriosis research continues to remain an extremely underfunded area of
35 women's health research, even after recent legislation increased endometriosis research
36 funding from \$13 million to \$26 million in 2020²⁷; and
37

38 Whereas, In 2022, endometriosis, a condition affecting approximately 11% of women, is
39 allocated only \$27 million of the \$45 billion NIH research budget, while inflammatory bowel
40 disease, a condition affecting 1.3% of all patients, is allocated \$195 million dollars for
41 research²⁸⁻³⁰; and
42

43 Whereas, Current AMA Policy H-525.988 currently supports increased funding for women's
44 health research, but fails to specifically highlight the dire need for endometriosis research and
45 does not take measurable action or advocacy to achieve these increases in research; and
46

47 Whereas, Endometriosis research continues to remain significantly underfunded since the
48 passage of this H-525.988 and its subsequent modification in 2010, indicating a persistent
49 policy gap and the need for an additional resolution to specifically address this gap for patients
50 with endometriosis; therefore be it

1 RESOLVED, Our AMA collaborate with stakeholders to recognize endometriosis as an area for
2 health disparities research that continues to remain critically underfunded, resulting in a lack of
3 evidence-based guidelines for diagnosis and treatment of this condition amongst people of color
4 (Directive to Take Action); and be it further

5
6 RESOLVED, Our AMA collaborate with stakeholders to promote awareness of the negative
7 effects of a delayed diagnosis of endometriosis and the healthcare burden this places on
8 patients, including health disparities among patients from communities of color who have
9 been historically marginalized (Directive to Take Action); and be it further

10
11 RESOLVED, Our AMA advocates for increased endometriosis research addressing health
12 disparities in the diagnosis, evaluation, and management of endometriosis (Directive to Take
13 Action); and be it further

14
15 RESOLVED, Our AMA advocates for increased funding allocation to endometriosis-related
16 research for patients of color, especially from federal organizations such as the National
17 Institutes of Health. (Directive to Take Action)

Fiscal Note: TBD

Relevant AMA Policy:

1. [Sex and Gender Differences in Medical Research H-525.988](#)
2. [An Expanded Definition of Women's Health H-525.976](#)
3. [Racial and Ethnic Disparities in Health Care H-350.974](#)
4. [Reducing Racial and Ethnic Disparities in Health Care D-350.995](#)
5. [8.5 Disparities in Health Care](#)

References:

1. World Health Organization. Endometriosis. www.who.int. Updated March 24, 2023. Accessed August 21, 2023. <https://www.who.int/news-room/fact-sheets/detail/endometriosis#:~:text=Overview,period%20and%20last%20until%20menopause>
2. Buck Louis GM, Hediger ML, Peterson CM, et al. Incidence of endometriosis by study population and diagnostic method: the ENDO study. Fertil Steril. 2011;96(2):360-365. doi:10.1016/j.fertnstert.2011.05.087
3. Ghiasi M, Kulkarni MT, Missmer SA. Is Endometriosis More Common and More Severe Than It Was 30 Years Ago? Journal of Minimally Invasive Gynecology. 2020 Feb;27(2):452-461. DOI: 10.1016/j.jmig.2019.11.018. PMID: 31816389.
4. Whiteman MK, Kuklina E, Jamieson DJ, Hillis SD, Marchbanks PA. Inpatient hospitalization for gynecologic disorders in the United States. Am J Obstet Gynecol. 2010;202(6):541.e1-541.e5416. doi:10.1016/j.ajog.2009.12.013
5. Eunice Kennedy Shriver National of Institute of Child Health and Human Development. www.nichd.nih.gov. How Common is Infertility? Last reviewed February 8, 2018. Accessed August 21, 2023. <https://www.nichd.nih.gov/health/topics/infertility/conditioninfo/common>.
6. Yale Medicine. www.yalemedicine.org. Polycystic Ovarian Syndrome. Accessed August 21, 2023. <https://www.yalemedicine.org/conditions/polycystic-ovary-syndrome>.

7. National Cancer Institute. seer.cancer.gov. Cancer Stat Facts: Cervical Cancer. Accessed August 21, 2023. <https://seer.cancer.gov/statfacts/html/cervix.html>.
8. Rahmioglu, N., Mortlock, S., Ghiasi, M. et al. The genetic basis of endometriosis and comorbidity with other pain and inflammatory conditions. *Nat Genet* 55, 423–436 (2023). <https://doi.org/10.1038/s41588-023-01323-z>.
9. Wessels, J.M., Domínguez, M.A., Leyland, N.A. et al. Endometrial microbiota is more diverse in people with endometriosis than symptomatic controls. *Sci Rep* 11, 18877 (2021). <https://doi.org/10.1038/s41598-021-98380-3>.
10. Mayo Clinic. www.mayoclinic.org. Endometriosis. Updated July 24, 2018. Accessed July 21, 2023. <https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656>.
11. Soliman AM, Fuldeore M, Snabes MC. Factors Associated with Time to Endometriosis Diagnosis in the United States. *J Womens Health (Larchmt)*. 2017;26(7):788-797. doi:10.1089/jwh.2016.6003
12. Buttram VC Jr. An expanded classification of endometriosis. *Fertil Steril*. 1978;30(2):240-242. doi:10.1016/s0015-0282(16)43467-9
13. Haas D, Shebl O, Shamiyeh A, Oppelt P. The rASRM score and the Enzian classification for endometriosis: their strengths and weaknesses. *Acta Obstet Gynecol Scand*. 2013;92(1):3-7. doi:10.1111/aogs.12026
14. Soliman AM, Fuldeore M, Snabes MC. Factors Associated with Time to Endometriosis Diagnosis in the United States. *J Womens Health (Larchmt)*. 2017;26(7):788-797. doi:10.1089/jwh.2016.6003
15. Agarwal SK, Chapron C, Giudice LC, et al. Clinical diagnosis of endometriosis: a call to action. *Am J Obstet Gynecol*. 2019;220(4):354.e1-354.e12. doi:10.1016/j.ajog.2018.12.039
16. Barnard ND, Holtz DN, Schmidt N, et al. Nutrition in the prevention and treatment of endometriosis: A review. *Front Nutr*. 2023;10:1089891. Published 2023 Feb 17. doi:10.3389/fnut.2023.1089891
17. Huijs E, Nap A. The effects of nutrients on symptoms in women with endometriosis: a systematic review. *Reprod Biomed Online*. 2020;41(2):317-328. doi:10.1016/j.rbmo.2020.04.014
18. Deepak Kumar K, Appleby-Gunnill B, Maslin K. Nutritional practices and dietetic provision in the endometriosis population, with a focus on functional gut symptoms. *J Hum Nutr Diet*. 2023;36(4):1529-1538. doi:10.1111/jhn.13158
19. Soliman AM, Surrey E, Bonafede M, Nelson JK, Castelli-Haley J. Real-World Evaluation of Direct and Indirect Economic Burden Among Endometriosis Patients in the United States. *Adv Ther*. 2018;35(3):408-423. doi:10.1007/s12325-018-0667-3
20. Soliman AM, Coyne KS, Gries KS, Castelli-Haley J, Snabes MC, Surrey ES. The Effect of Endometriosis Symptoms on Absenteeism and Presenteeism in the Workplace and at Home. *J Manag Care Spec Pharm*. 2017;23(7):745-754. doi:10.18553/jmcp.2017.23.7.745
21. Nnoaham KE, Hummelshoj L, Webster P, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril*. 2011;96(2):366-373.e8. doi:10.1016/j.fertnstert.2011.05.090
22. Bougie O, Yap MI, Sikora L, Flaxman T, Singh S. Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis. *BJOG*. 2019;126(9):1104-1115. doi:10.1111/1471-0528.15692
23. Edi R, Cheng T. Endometriosis: Evaluation and Treatment. *Am Fam Physician*. 2022;106(4):397-404.
24. Practice bulletin no. 114: management of endometriosis. *Obstet Gynecol*. 2010;116(1):223-236. doi:10.1097/AOG.0b013e3181e8b073

25. American Society for Reproductive Medicine. Current Evaluation of Amenorrhea (2008). [www.asrm.org](https://www.asrm.org/practice-guidance/practice-committee-documents/current-evaluation-of-amenorrhea/?_t_id=oWb-jHJn0ZwBsy2AG8yHnQ==&_t_uuid=s9ahrpCHSdKlktZPwCK6qA&_t_q=endometriosis&_t_tags=siteid:01216f06-3dc9-4ac9-96da-555740dd020c,language:en,andquerymatch&_t_hit.id=ASRM_Models_Pages_ContentPage/_dad965ac-78ec-4d64-8848-1b3c2584d9ae_en&_t_hit.pos=1). Accessed August 21, 2023. https://www.asrm.org/practice-guidance/practice-committee-documents/current-evaluation-of-amenorrhea/?_t_id=oWb-jHJn0ZwBsy2AG8yHnQ==&_t_uuid=s9ahrpCHSdKlktZPwCK6qA&_t_q=endometriosis&_t_tags=siteid:01216f06-3dc9-4ac9-96da-555740dd020c,language:en,andquerymatch&_t_hit.id=ASRM_Models_Pages_ContentPage/_dad965ac-78ec-4d64-8848-1b3c2584d9ae_en&_t_hit.pos=1
26. Ellis K, Munro D, Clarke J. Endometriosis Is Undervalued: A Call to Action. *Front Glob Womens Health*. 2022 May 10;3:902371. doi: 10.3389/fgwh.2022.902371. PMID: 35620300; PMCID: PMC9127440.
27. Endometriosis Foundation of America. U.S. House Approves Doubling Funding for Endometriosis Research to \$26 Million Annually. www.endofund.org. Posted July 31, 2020. Accessed August 21, 2023. <https://www.endofund.org/u.s.-house-approves-doubling-funding-for-endometriosis-research-to-26-million-annually>
28. Centers for Disease Control and Prevention. Prevalence of IBD. www.cdc.gov. Reviewed April 14, 2022. Accessed August 21, 2023. <https://www.cdc.gov/ibd/data-and-statistics/prevalence.html>
29. NIH Report. Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). report.nih.gov. Published March 31, 2023. Accessed August 21, 2023. <https://report.nih.gov/funding/categorical-spending#/>
30. National Institutes of Health. Budget. www.nih.gov. Reviewed August 1, 2023. Accessed August 21, 2023. <https://www.nih.gov/about-nih/what-we-do/budget>
31. American Journal of Managed Care. Racial Disparities Associated With Endometriosis Diagnosis. Accessed September 20, 2023. <https://www.ajmc.com/view/racial-disparities-associated-with-endometriosis-diagnosis>