

LETTER TO THE EDITOR

We write with substantive concerns regarding the assumptions made in the recent editorial ‘Worth waiting for?’ published in the *Australian and New Zealand Journal of Obstetrics and Gynaecology*¹ – assumptions the publication states should be avoided.

The first is that endometriosis is a homogenous condition, when the weight of evidence is there are different disease states and presentations with differing clinical outcomes.²

Second, endometriosis is reduced to a chronic pain presentation, when the undeniable biological characteristics preclude such simplification. This is reflected in the core outcome set for research in endometriosis, where quality of life, fertility outcomes and systemic symptoms are also recommended for inclusion.³ Additionally, somatic cellular changes in endometriosis similar to those demonstrated in malignancy⁴ are (appropriately) of considerable concern as they may predispose some types of endometriosis to future risks of ovarian, breast and endometrial cancers.⁵ Importantly, this biological risk is present in endometriosis patients and not in those with persistent pelvic pain (PPP) without lesions.

Third, the editorial claims lesions regress or remain stable regardless of endometriosis subtype/stage. Closer inspection of these data identifies that it is superficial/mild disease that is disproportionately more likely to regress compared to deep disease, and this has been postulated for decades.⁶ Deeply invasive disease has long been considered a distinct entity, and while there are calls for more confirmatory research,⁷ 24 surgical randomised controlled trials (RCTs) provide considerable evidence of improvement in pain symptoms and quality of life⁸ when this modality is used.

Fourth, the suggestion that there is inequity for people with PPP compared with endometriosis is unsubstantiated. Gonadotropin-releasing hormone agonists are Pharmaceutical Benefits Scheme (PBS)-subsidised for endometriosis in Australia since data support an improvement in outcomes. Conversely, Mirena, some hormonal contraceptives and dienogest have supportive data for use in patients with endometriosis and are not PBS-subsidised. In contrast, gabapentin is PBS-subsidised in Australia for persistent pain states, despite an RCT demonstrating it is no more efficacious than placebo for patients with PPP where endometriosis is excluded.⁹

Fifth, the claim that the absence of endometriosis at surgery automatically invalidates those with no lesions is purely speculative, requiring substantiating evidence or appropriate guidance for practitioners managing PPP. We note the absence of such evidence-based guidelines. However, published evidence-based guidelines for endometriosis include the Australian,¹⁰ European Society of Human Reproduction and Embryology¹¹ and National Institute for Health and Care Excellence¹² documents that systematically appraise the current evidence and gaps. Disappointingly





none are cited in the editorial. These guidelines clearly define themselves as endometriosis-specific; do not recommend surgical confirmation of endometriosis (contrary to the claim in the editorial); recommend non-invasive and symptom-based treatments as first line; support multi-disciplinary care; include statements on non-pain outcomes that are endometriosis-specific; and very importantly call for ongoing collaborative research. By contrast, the recent statement from the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists (ANZCA)¹³ is completely dismissive of endometriosis as a cause of pain in any circumstance; is ignorant of the science that refutes such statements; and fails to offer alternative treatment pathways for PPP. Unsurprisingly, the ANZCA statement and a mainstream media release¹⁴ has led to substantive backlash on social media from people with endometriosis again feeling that the medical community is gaslighting them. This statement is baseless when the evidence is that the time to diagnosis (and treatment) of endometriosis has halved in the last two decades;¹⁵ the Australian government is funding 22 endometriosis and pelvic pain primary care clinics across the country; and for the first time, there has been substantial and specific investment in endometriosis and pain research. It could be argued that this would not exist at all if not for the relentless efforts of endometriosis patients, researchers, clinicians and advocates pushing that agenda.

It is disappointing that the authors have chosen to present a divisive assault when our patients deserve a unified approach to the many unknowns for both endometriosis and PPP. While we agree that surgeons treating endometriosis need to acknowledge and address PPP in its own right, we also advocate that pain physicians treating PPP need to acknowledge and address endometriosis as a potential contributor. Regressive, oppositional and unsubstantiated statements alienate not only those we aim to help, but also the profession and funding organisations, including government agencies. Advocating for the indiscriminate cancellation of surgical interventions despite the evidence is petty politics. Perhaps instead of trying to sink the boat that has taken decades to build, the authors and their supporters should swim toward it, where they'll find us throwing a lifesaver to bring them aboard.

CONFLICT OF INTEREST

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REFERENCES

- Joseph K, Kite L, Grover S, Druitt M. Worth waiting for? *Aust N Z J Obstet Gynaecol* 2024; <https://doi.org/10.1111/ajo.13869>.
- Zondervan KT, Becker CM, Missmer SA. Endometriosis. *N Engl J Med* 2020; **382**: 1244–1256. <https://doi.org/10.1056/NEJMr a1810764>.
- Duffy J, Hirsch M, Vercoe M *et al.* A core outcome set for future endometriosis research: An international consensus development study. *BJOG* 2020; **127**: 967–974. <https://doi.org/10.1111/1471-0528.16157>.
- Anglesio MS. Cancer-associated mutations in endometriosis without cancer. *N Engl J Med* 2017; **376**: 1835–1848.
- Al-Badawi IA *et al.* Association between Endometriosis and the risk of ovarian, endometrial, cervical, and breast cancer: A population-based study from the U.S. National Inpatient Sample 2016–2019. *Curr Oncol* 2024; **31**: 472–481. <https://doi.org/10.3390/curroncol31010032>.
- Brosens IA, Puttemans P, Deprest J, Rombauts L. The endometriosis cycle and its derailments. *Hum Reprod* 1994; **9**: 770–771. <https://doi.org/10.1093/oxfordjournals.humrep.a138594>.
- Endometriosis Initiative G. A call for new theories on the pathogenesis and pathophysiology of endometriosis. *J Minim Invasive Gynecol* 2024; **31**: 371–377. <https://doi.org/10.1016/j.jmig.2024.02.004>.
- Abbott J, Billow M, Gallant T *et al.* Patient-reported outcome measures used in randomized controlled trials following surgical intervention for Endometriosis: A structured review from the AAGL practice guidelines group. *J Minim Invasive Gynecol* 2024; **31**: 71–83.e17. <https://doi.org/10.1016/j.jmig.2023.10.017>.
- Horne AW, Vincent K, Hewitt CA *et al.* Gabapentin for chronic pelvic pain in women (GaPP2): A multicentre, randomised, double-blind, placebo-controlled trial. *Lancet* 2020; **396**: 909–917. [https://doi.org/10.1016/S0140-6736\(20\)31693-7](https://doi.org/10.1016/S0140-6736(20)31693-7).
- Australian clinical practice guideline for the diagnosis and management of endometriosis. RANZCOG, Melbourne, Australia. 2021. [Accessed 6 August 2024.] <https://ranzcog.edu.au/wp-content/uploads/2022/02/Endometriosis-clinical-practice-guide-line.pdf>
- Becker CM, Bokor A, Heikinheimo O *et al.* ESHRE guideline: Endometriosis. *Human Reproduction Open* 2022; **2022**: hoac009.
- National Guideline Alliance (UK). *Endometriosis: Diagnosis and Management. National Institute for Health and Care Excellence: Guidelines*. London: National Institute for Health and Care Excellence (NICE), 2017.
- ANZCA. *Statement on Pelvic Pain and Endometriosis*: Faculty of Pain Medicine, 2024. [Accessed 6 August 2024.] <https://www.anzca.edu.au/news/persistent-pelvic-pain-statement-approved>
- Eddie R. *Waste of money: Pain specialists challenge endometriosis surgeries*. 2024 <https://www.smh.com.au/politics/victoria/waste-of-money-pain-specialists-challenge-endometriosis-surgeries-20240731-p5jxz0.html>.
- Armour M, Sinclair J, Ng CHM *et al.* Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: An Australian survey. *Sci Rep* 2020; **10**: 16253 <https://doi.org/10.1038/s41598-020-73389-2>.