

20<sup>th</sup> June 2022

Dr Benjamin Bopp  
President  
The Royal Australian and New Zealand College of Obstetrics and Gynaecologists  
Sent via email: [ranzcoq@ranzcoq.edu.au](mailto:ranzcoq@ranzcoq.edu.au)

Dear Dr Benjamin Bopp,

## Re: Call for revision of the RANZCOG Endometriosis Clinical Guidelines

Endometriosis Western Australia is a not-for-profit support and advocacy organisation that represents the interests of those living with endometriosis in Western Australia, supporting more than 4,500 members through our online support group alone. We acknowledge and appreciate the efforts of RANZCOG members in creating our existing endometriosis clinical guidelines. However, we believe the current guidelines fail to address the needs of the endometriosis community for many reasons, including recent advancements in research, a lack of guidance for pain management and minimal community consultation during their creation.

Our organisation recently sought feedback from the community about their concerns with the guidelines in the current form, and what they would like to see in the next iteration. The following is a summary of their concerns and recommendations.

### 1. Access to appropriate surgical intervention

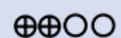
Concerns regarding the current level of access to surgery and the type of surgery provided was a primary concern of all our members. We see this reflected in discussions that take place on social media and in our private online support group. The specific concerns provided include the following:

#### 1.1 Access to excision

All our members were concerned about the current level of access to specialised excision surgery, and the use of ablation to treat deeply infiltrative endometriosis. Some people shared personal stories of having received sometimes multiple ablative procedures with no relief of symptoms, only to learn about excision techniques years later and undergo repeat surgery with far better outcomes. The primary demand from the community is that excision surgery be offered to all people with endometriosis. This is especially important for people with deeply infiltrative endometriosis, who are not often provided with pre-operative assessments including specialised ultrasound or MRI imaging, and so are not appropriately triaged to the appropriate advanced laparoscopic surgeon. The 2022 ESHRE guidelines support an excision focused approach (section II.3.b),

#### *Recommendation (25)*

**When surgery is performed, clinicians may consider excision instead of ablation of endometriosis to reduce endometriosis-associated pain.**



further clarified by stating “The excisional approach is likely to be more suitable for deep endometriosis lesions, as it is impossible to know if the entire lesion is destroyed with ablative techniques.”<sup>1</sup>

### 1.2 Repeated and multiple surgeries

Related to the above concerns, many members were distressed at the number of surgeries performed by less experienced surgeons before they were able to access an excision expert. Some members report 6 months or less between surgical interventions. Members postulate this is due to an inability to recognise endometriotic lesions, the use of ablative techniques, or generally substandard treatment. They would like people to receive their first surgical intervention from trained endometriosis experts.

### 1.3 Guidelines for surgically complex cases

The current guidelines are sparse on specific recommendations for involvement of pelvic organs such as the ovaries or rectum, or on surgical techniques for endometriosis outside the pelvis. The ESHRE guidelines contain extensive information on ovarian endometriosis (II.3.e) and bowel endometriosis (II.3.f.1), and discuss the signs and symptoms suggestive of extra-pelvic disease (VII.1.b) that would necessitate a multidisciplinary approach.<sup>1</sup> Our members are concerned that only their pelvic endometriosis is being detected and treated and believe the guidelines must address how this can be diagnosed.

### 1.4 The use of adjunct hormonal therapies

Our members believe the use of medication, particularly hormonal medication, is too heavily relied upon as a way to avoid or unnecessarily delay surgery. Some report that surgery wasn't offered as an option unless they agreed to a trial, with concerns about coercion. Some people decide they would like surgery before or during their initial consult and are still placed on hormonal therapy, which is not supported in the ESHRE guidelines (II.4.a),<sup>1</sup>

#### *Recommendation (35)*

**It is not recommended to prescribe preoperative hormone treatment to improve the immediate outcome of surgery for pain in women with endometriosis.**



or the NICE decision aid “Hormone treatment for endometriosis symptoms – what are my options?”<sup>2</sup>

This decision aid covers hormonal contraceptives because they are the first kind of treatment for endometriosis symptoms most women are asked to think about trying, in addition to pain-killers. **You do not have to try hormone treatment.**

Our members would like more autonomy with regards to their treatment options and a more well-rounded education from clinicians on the reasons and risks in prescribing this medication from the outset.

## 2. Improving early diagnosis

The diagnostic delay is well recognised, an experience that is reflected in the stories of our members. This was variably due to delay at the general practitioner level, to lack of recognition in emergency departments, and due to gynaecologists in rural and remote areas being inexperienced in the recognition of the varied presentations of endometriosis. Our members identified two areas they would like to see addressed in the new guidelines to help reduce this delay.

## 2.1 Community specific guidelines

Most of our members report the diagnostic delay occurring at the primary care level, or between primary and specialist care. Our rural members report underdiagnosis and misdiagnosis by specialist services in rural areas. This includes both a lack of knowledge about endometriosis, a lack of clarity about how and where to refer patients, and what the most appropriate investigations are pending a specialist appointment. They would like to see guidelines that comprehensively address the symptoms such as those in the ESHRE guidelines (I.1),<sup>1</sup>

### *Recommendation (1)*

**The GDG recommends that clinicians should consider the diagnosis of endometriosis in individuals presenting with the following cyclical and non-cyclical signs and symptoms: dysmenorrhea, deep dyspareunia, dysuria, dyschezia, painful rectal bleeding or haematuria, shoulder tip pain, catamenial pneumothorax, cyclical cough/haemoptysis/chest pain, cyclical scar swelling and pain, fatigue, and infertility.**

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and that address that detection can be challenging, such as in the NICE Guidelines (1.5).<sup>3</sup>

**Do not exclude the possibility of endometriosis if the abdominal or pelvic examination, ultrasound or MRI are normal.**

A clear guide to aid development of streamlined local referral pathways would also be beneficial, particularly highlighting signs that are suggestive of deeply infiltrative endometriosis that would require the attention of a specialist centre. This could also specifically address rural areas, including early recognition of complex cases and cases finding no relief from local management, that may require a referral to subspecialist centres.

## 2.2 Increased recognition of adolescents

Many our members report having symptoms begin in adolescence, some as early as menarche. Despite this, many were told that they were too young to have developed endometriosis, or that they are too young for surgery. This is contrary to evidence, with ESHRE recommending (V.1.c),<sup>1</sup>

### *Recommendation (72)*

**In adolescents, clinicians should take a careful history and consider the following symptoms as suggestive of the presence of endometriosis:**

- chronic or acyclical pelvic pain, particularly combined with nausea, dysmenorrhea, dyschezia, dysuria, dyspareunia
- cyclical pelvic pain.

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and (V.2.b).



*Recommendations (82-83)*

<p><b>In adolescents with endometriosis, clinicians may consider surgical removal of endometriosis lesions to manage endometriosis-related symptoms. However, symptom recurrence rates may be considerable, especially when surgery is not followed by hormone treatment.</b></p>	<p>⊕○○○</p>
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<p><b>The GDG recommends that if surgical treatment is indicated in adolescents with endometriosis, it should be performed laparoscopically by an experienced surgeon, and, if possible, complete laparoscopic removal of all present endometriosis should be performed.</b></p>	<p>GPP</p>
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Members would like adolescents to be specifically addressed to prevent this early diagnostic delay.

**3. The use of gender inclusive language**

Our members and our organisation value, welcome, and respect our trans and non-binary peers, and recognise their additional barriers to seeking gender appropriate care and support. At an organisational level this has been reflected in the name of our support group changing from “Endometriosis Perth Sisterhood of Support” to “Endometriosis Western Australia WArriors”. We also avoid the use of gendered language in all our official documentation and communications. Our members reflected this value in their feedback, with two specific recommendations.

**3.1 Gender neutral language**

To date, we are not aware of any guidelines who have incorporated this change of language to recognise this disease affects more than women. This is despite both calls from the community to recognise these people (for example, reported by [Endo Found](#)<sup>4</sup> and the [CBC](#)<sup>5</sup>). It is recognised that endometriosis is historically a gynaecological “women’s” issue, but with our increasing awareness of gender diversity this is no longer the case. There are multiple ways this can be addressed, with examples including replacing “women” with “people”, or clarifying “women and a number of trans and non-binary individuals”

**3.2 Moving away from describing endometriosis as a menstrual disorder**

Endometriosis is a complex disease, and while it is acknowledged many people living with disease experience cyclical symptoms related to menstruation, this is certainly not the case for all people. Chronic pain unrelated to the stage of the menstrual cycle is frequently reported our members. Symptoms persisting despite treatment that suppresses menstruation is common. The disease is so enigmatic that our members highlighted their awareness of the disease being found in people assigned male at birth, discussed at [Extrapelvic Not Rare](#).<sup>6</sup> While we understand in depth discussion may not be relevant for a gynaecology focused guideline, the members have asked for it to be acknowledged.

**4. The association with ovarian cancer**

Our members were very concerned that the correlation between endometriosis and ovarian cancer was largely dismissed in the Australian guidelines without more extensive examination of the literature.

There is a significant body of research examining the potential links, and while research quality may be inconsistent, our members do not want it ignored. The new ESHRE guidelines have the benefit of additional years of research to comment on, and have the following recommendations (multiple recommendations from section X. Endometriosis and Cancer).<sup>1</sup>

*Recommendation (104)*

**Clinicians should inform women with endometriosis requesting information on their risk of developing cancer that endometriosis is not associated with a significantly higher risk of cancer overall. Although endometriosis is associated with a higher risk of ovarian, breast, and thyroid cancers in particular, the increase in absolute risk compared with women in the general population is low.**

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*Recommendations (107-108)*

**In women with endometriosis, clinicians should not systematically perform cancer screening beyond the existing population-based cancer screening guidelines.**

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**Clinicians can consider cancer screening according to local guidelines in individual patients that have additional risk factors, e.g., strong family history, specific germline mutations.**

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*Recommendation (109)*

**Clinicians should be aware that there is epidemiological data, mostly on ovarian endometriosis, showing that complete excision of visible endometriosis may reduce the risk of ovarian cancer. The potential benefits should be weighed against the risks of surgery (morbidity, pain, and ovarian reserve).**

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Recommendations published in [The Lancet](#) in 2017 also summarise the available information in a patient focused format that recognise the link.<sup>7</sup>



## Panel: Key messages for clinicians addressing the concerns of women with endometriosis about ovarian cancer risk

### Am I going to get ovarian cancer?

- Most women with endometriosis never develop ovarian cancer. Although several studies report an increased ovarian cancer risk, evidence suggests that the overall likelihood of you developing ovarian cancer is low. Thus, you should be aware of, but not worried about, the effect of endometriosis on your ovarian cancer risk.
- Although 1.3% of women in the general female population will develop ovarian cancer in their lifetime, this proportion is still less than 2% in women with endometriosis. Thus, although the risk is increased, your lifetime risk is low and is not substantially different from that in women without endometriosis. To put the risk in perspective, according to recent estimates, 39% of women who inherit a harmful BRCA1 mutation and 11–17% who inherit a harmful BRCA2 mutation—the rare genes that predispose to breast cancer—will develop ovarian cancer by 70 years of age. Furthermore, as a woman in the general population, your risks of breast (12%), lung (6%), and bowel (4%) cancers are still higher than your risk of developing ovarian cancer.
- Certain types of ovarian cancer are more commonly associated with a history of endometriosis. These endometriosis-associated cancers tend to be detected at an earlier stage and have a better prognosis than other types of ovarian cancer.

### What can I do to lower my cancer risk?

- No clear evidence exists that transvaginal ultrasound or serum CA-125 measurements can detect ovarian cancers early or that risk-reducing surgery to remove the ovaries can save lives. Generally, to improve health and reduce the risk of cancer, try to have a balanced diet with low intake of alcohol, exercise regularly, maintain a healthy weight, and do not smoke.

Members are also aware of the genetic correlation between endometriosis and some ovarian cancers including endometrioid ovarian cancer, clear cell ovarian cancer, and potentially high grade serous ovarian cancer, which was recently described in the literature by Queensland researchers [Dr Sally Mortlock et al.](#)<sup>8</sup>

## 5. Recognition of common associated conditions

Most of our members who provided feedback describe having comorbidities as a result of their experiences living with endometriosis. They would like to see these acknowledged more in the new guidelines.

### 5.1 Pain

Chronic pain is a well-recognised comorbidity of endometriosis. Our members would like to see a more detailed discussion around the pain associated with endometriosis, and recommendations for pain management that are tailored to specific presentations. The ESHRE guidelines discuss this extensively in Section II.1 to II.6.<sup>1</sup>

### 5.2 Mental illness

Mental illness and negative effects on emotional wellbeing are a well described consequence of living with endometriosis. This is described in multiple sections of the ESHRE guidelines, including in the Introduction and as a focus of long-term monitoring. Mental health is briefly mentioned in the NICE guidelines when discussing lifestyle interventions, with two further mentions of emotional wellbeing. The current RANZCOG guidelines mention this aspect of living with the disease only briefly when discussing the provision of information and support, and in the context of delayed diagnosis/misdiagnosis. A revised guideline would likely benefit from a greater focus on the risk of negative mental impacts not only at the time of diagnosis, but as a consequence of living with chronic illness.

### **5.3 Permanent disability**

While most of our members report some degree of reduced function due to their symptoms, some members report profound disability due to unmanageable pain, the effects on other organ systems due to deeply infiltrative or extra pelvic endometriosis, or the associated mental illness. This is something that could be recognised in new guidelines.

## **6. The use of GNRH agonists i.e. Zoladex**

Our members report concerns about the use of GNRH agonists given the severe side effects. Feedback varied from concerns about the use prior to confirmation of diagnosis, concerns about the long-term effects of prolonged use beyond 3-6 months, to dissatisfaction with it being offered as a treatment option at all. They would like a review of the use of these medications, better counselling of the risk and benefit for people offered this therapy particularly without a confirmed diagnosis, and clearer discussion of duration.

## **Other recommendations**

Our members also had several recommendations on actions that RANZCOG could propose and work toward in conjunction with other organisations. These included:

### **1. Make “endometriosis specialist” a protected term.**

Many members were concerned that practitioners from surgeons to CAM professionals can advertise themselves as specialised in endometriosis, without any specific training. They would like a way to be reassured they are choosing the right team.

### **2. Increase the number of expert surgeons.**

Our members would like to see more training positions for advanced laparoscopic surgeons, with a focus on effectively detecting and treating endometriosis, and see more of them in publicly accessible positions.

### **3. Consider making endometriosis a subspecialty.**

Some members report that despite being excellent surgeons, their chosen specialist did not have a good understanding of how to treat endometriosis. It was suggested that endometriosis may be complex enough to require its own subspecialisation.

### **4. Improve access to treatment through Medicare and the PBS.**

Some recommended treatments, such as pelvic floor physiotherapy and Visanne, are prohibitively expensive for people whose income is affected by this disease. Increased rebates would help ease this burden.

**5. Increase awareness in general practice and in rural and remote areas.**

An increased focus on endometriosis in training through the RACGP and ACCRM could help prevent the diagnostic delay by facilitating early recognition, referral, and treatment.

**6. Recognise endometriosis as a cause of disability.**

Many of our members are unable to work due to their symptoms, particularly while waiting for access to intervention in the public system. Their only form of financial support is often JobSeeker, which is often not appropriate. They would like to see endometriosis recognised as a condition eligible for the Disability Support Pension if other criteria are met.

Endometriosis Western Australia is dedicated to advocating for Western Australians living with endometriosis. We appreciate your time and your efforts in developing Australian specific guidelines, but we believe that now is the time for significant revision to meet the needs and expectations of our diverse and well-educated community.

Our organisation is always available for consultation, and we are happy to facilitate direct consultation with our members. If there is anything else our organisation can do to assist with the development of a patient focused revision, we can be reached at [info@endometriosiswa.org.au](mailto:info@endometriosiswa.org.au). We welcome the development of an ongoing relationship between our organisations and look forward to your future correspondence.

Yours sincerely,



**Endometriosis**  
Western Australia Inc.

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