Consultation RANZCOG Draft Guideline: Australian Living Evidence Guideline: Endometriosis

1 Demographics (2) Guideline Feedback Form

Guideline feedback form

We recommend that you access the DRAFT **Australian Living Evidence Guideline: Endometriosis** document on a separate desktop computer using a web browser.

Please answer each of the 15 multiple-choice questions below.

There are two tables at the end of the survey to allow free text for further feedback if you wish.

- For the first table, please respond according to the page number of the guideline document and provide citations for evidence supporting your comments.
- For the second table, please respond with any other general feedback for the overall guideline.

This form will time-out if unattended so please use the *Save and Resume* function as you go.

Please contact **endometriosisguideline@RANZCOG.edu.au** if you have any issues accessing the document.

1. The Guideline sufficiently covers the topic scope for diagnosis and management of endometriosis.

- ○ Strongly Agree
- ◉ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly Disagree

Screenshot

2. The Guideline recommendations adequately address the signs and symptoms associated with endometriosis.

- ○ Strongly Agree
- ◉ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly Disagree

3. The Guideline recommendations adequately address the information and support, prompt diagnosis and organisation of care needs of people with suspected or diagnosed endometriosis.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

4. The Guideline recommendations adequately address the referral to secondary care needs of people with suspected or diagnosed endometriosis.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

5. The Guideline recommendations adequately address the diagnosis of endometriosis.

- ○ Strongly Agree
- ◉ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly Disagree

6. The Guideline presents clear recommendations on the use of analgesics.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

7. The Guideline presents clear recommendations about hormonal management.

- ○ Strongly Agree
- ◉ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly Disagree

8. The Guideline presents clear recommendations about surgery.

- ○ Strongly Agree
- ◉ Agree
- ○ Neutral
- ○ Disagree
- ○ Strongly Disagree

9. The Guideline presents clear recommendations about non-surgical and non-pharmacological management options for endometriosis.

- ○ Strongly Agree
- ○ Agree
- ◉ Neutral
- ○ Disagree
- ○ Strongly Disagree

10. The Guideline presents clear recommendations about follow up and secondary prevention options for endometriosis.

- ○ Strongly Agree
- ○ Agree
- ◉ Neutral
- ○ Disagree
- ○ Strongly Disagree

11. The Guideline presents clear recommendations about management options for adolescents.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

12. The evidence base behind the Guideline recommendations is clear according to available research.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

13. The diagnosis and management flowchart provides clear guidance for the management of endometriosis.

- ○ Strongly Agree
- ○ Agree
- ○ Neutral
- ◉ Disagree
- ○ Strongly Disagree

14. Would you consider this guideline useful for clinical consultations?

◉ Yes ○ No

15. Are there adequate special considerations for higher-risk population groups or specific population groups (i.e. First Nations people)?

○ Yes ◉ No

Feedback table

If you have specific comments about the draft guideline recommendations, please provide these below by noting the page number that you are responding to and then add the comment in the corresponding box.

Please provide citations or references for any comments where possible.

	Page number	Comments
⊗	13	CQ2:The conditional recommendations are more in line with the evidence-based approach to managing chronic pain conditions either related or not related to endometriosis.
⊗	13	When assessing those presenting with pain and/or viscero-visceral hyperalgesia related conditions (for example, Irritable Bowel Syndrome, vaginismus and bladder overactivity/irritability), it is essential that socio-psycho-biomedical model of care is applied. In the above assessment, the need for psychological health assessment rather than assessment of patient's emotional needs is crucial and required for trauma-informed care approach.
⊗	12	Introduction of concept of viscera-visceral hyperalgesia and central sensitisation that produces many of the symptoms listed in point 1, would be helpful when discussing recommendation in point 6. This would be a powerful way introducing this concepts to primary health care clinicians and general gynaecologists, prompting further education opportunities for the professionals and their patients.
⊗	14	We agree agree with the above statement re multidisciplinary pain management services. Though the practicality of provision of services for women with chronic pain is usually a referral to a pain specialist privately or a referral to a allied health led or specialist led pain management services in the public sector. There are less than 10 services across Aus/NZ with any expertise in pelvic pain. Thus the recommendation has limited value.
⊗	14	'Multidisciplinary pain services with expertise in pelvic pain": We advocate that multidisciplinary pain services should aim to have a close relationship with the local gynaecology services with expertise in biomedical management of chronic pelvic pain. The aim should be to develop interdisciplinary clinics between these services and should be established as Hubs of clinical expertise to facilitate the coordinated approach to this complex patient cohort

		patient cohort
⊗	15	CQ6:The FPM position statement suggests that women who have chronic pelvic pain should be offered interdisciplinary management on presentation. This can be primary or secondary/tertiary care led, but active symptom management should be offered in conjunction with any other medical and/or surgical management. This is further explored in CQ8 recommendation and, perhaps, this should be combined or switched in the document.
⊗	17	Point 26. What is meant by referral for further management? Who should the referral be made to? Does this suggest a referral to a pain specialist? As this is a guideline on management, this should be made more explicit
⊗	17	Point 28 refers to management of acute pain with opioids. If Faculty was considering endorsement of this document, than it would be important to ensure that acute pain (ie in context of post-operative recovery) is not confused with chronic pain (ie what the document refers to for most of the time as simply pelvic pain, thus the confusions)). If the opioid treatment is to be considered for chronic pelvic pain than the FPM statement on this could be referred to as an Aus/NZ consensus on opioid use
⊗	17	NSAID trial: Generally, 3 months would not be considered a short trial of a medication including NSAID. The recommendation for use of NSAIDs for 3 months as a short trial without PPI cover & without clear mention of maximum doses & days of use can increase further morbidity in women with chronic pain and lead to GI related symptoms. The advise about medication use in a guideline should not come without evidence behind it, particular for medications that are frequently associated with misuse & SE
⊗	17	(cont above) in this cohort. The recommendation about 'neuromodulator treatment' is unclear and seems to suggest that these are also used in management for depression and anxiety in higher doses. This is certainly untrue for anti-epileptics such as pregabalin and gabapentin.
⊗	17	The guideline jumps around grouping analgesics and then mentioning opioids and medical cannabis in separate sections. The guideline would benefit from having a combined section on managing pain in women with endometriosis or with suspected endometriosis. The authors were able to do that for infertility.
⊗	17	The discussion about medical cannabis is timely in this guideline, though it does make an assumption that both general practitioners and gynaecologists should have understanding of the regulations and legal frameworks around its prescription and also understand the evidence around its use. There is no specific chronic pelvic pain or endometriosis related evidence for or against medical cannabis, and thus we would argue that this discussion is outside the normal gynaecological/GP practice
⊗	17	(cont above) and an opinion of pain specialist should be sought for further advise. Meanwhile, a reference to TGA and FMP websites may provide enough information for a patient.
⊗	25	The guideline suggests in point 77 that all non-opioid analgesic options are suitable for adolescent population. In the context of this guideline, the 'neuromodulators', 3 months trial of NSAIDs and medical cannabis have been discussed as analgesic options. The use of TCAs and pregabalin/gabapentin would be outside the usual recommendations for adolescent age group. Medical cannabis should be avoided all together.
⊗	25	Point 77 - This point should be re-worded and clarified as simple analgesia or paracetamol + ibuprofen due to safety concerns.
⊗	17	There should be a warning against slow-release/modified release opioid use in both acute and chronic pain, as this is associated with increased risk of dependence (see FPM statement on opioid use).

This guideline is a significant step towards improving healthcare for women (with or without endometriosis) though none of them are acknowledged in this GDG as those suffering from persistent or chronic pelvic pain.

This is the first RANZCOG-led guideline stating that laparoscopy is no longer first-line diagnostic tool for women with symptoms of pelvic pain. This is in line with other emerging literature and guidelines, and a very welcome change in direction of diagnosis and management of endometriosis.

Pelvic pain is used as a descriptor throughout the document, so when acute pain is thrown in half-way, the guideline really becomes a bit confusing. We question why chronic/persistent pelvic pain is not included as part of the symptoms, as certainly that is very dismissive of women's symptoms and the literature around this and medically inaccurate.

This guideline widens the symptoms to more broader categories. It would be helpful to acknowledge in this section, as stated in Part A summary of the document, that some people with endometriosis do not experience any pain or other debilitating symptoms. For the completion, it would be helpful to give a percentage of the patients with endometriosis not experiencing symptoms quoted in recent literature.

The guideline is somewhat drifting from point to point and can be repetitive in parts and divides some topics unnaturally eg management of pain is mentioned in many different sections of GDG and this makes it a little messy and hard to follow. Unfortunately, that is likely the result of trying to separate the topic of endometriosis from chronic pelvic pain.

The language of the guideline is not uniform – it drifts from technical medical language ('neuromodulators', NSAIDs) to lay-man terms such as emotional needs. Getting a consistency across the guideline would be helpful.

A patient information/summary should be provided in appropriate non-technical level-appropriate language.

It would be important to introduce a concept of viscera-visceral hyperalgesia and central and peripheral sensitisation resulting in the 'other symptoms' of endometriosis. This is so that the next edition of GDG picks up a more on it and explores the relationship between pain and related symptoms of bowel and bladder irritability etc.

A short 3-line statement on multidisciplinary care remains vague and non-descriptive and misses opportunity to guide change in national priorities around women's health.

Overall, we welcome the direction of this guideline away from very solid biomedical approach to a discussion of evidence-based risks and benefits of this options. There is also a shift (though this can be lost in the current structure of GDG) to advocate for assessment and management of women's individual symptoms in manner that lines closer with the women's goals for their health and life (next edition may even talk about patient-focused goals and co-ownership of the decision making process).

We have structured the summaries of the comments from our members under the headings of the topics in each question above. The specific comments are also provided under in the table of pages and comments.

Question 4:

There is little to no discussion of the referral pathways/specialities involved

The addition of recommendation (in CQ1: 4 Good Practice Point) of pelvic examination benefits and risks, including discomfort, and furthermore trigger of pelvic pain, is again welcome. It restores women's autonomy and also acknowledges that pelvic examinations may not be appropriate in the context of already significant pelvic pain outside acute context.

Question 8:

There is a welcome change in this guideline recommending that the surgical management is directed at the removal of endometriotic lesions. And that the removal of these lesions may or may not improve symptoms. It also warns against re-operating.

It is also the first guideline to openly state that hysterectomy in people with endometriosis has very limited evidence for improving patient outcomes, particularly pain. It also states that there is no evidence that hysterectomy for adenomyosis will or will not improve pain.

We are somewhat startled to see that there is no examination of the evidence for the efficacy of surgery/outcomes following surgery. There is a question pertaining to it, but the answer only really addresses excision vs ablation. It would be very important for this evidence to be properly appraised in the guideline.

A key question for the guideline group to explore in developing this is "who would benefit from surgery"- what factors can be identified which predict benefit or harm from surgical intervention and how can this be practically screened for in clinical practice.

The phrase "discuss the role of laparoscopy" is vague, and does not include that this discussion should include the transparent explanation of the current equipoise in the evidence nor that this is the subject of a number of randomised controlled trials to

establish efficacy. Such open disclosure is essential as a component of providing informed consent.

Question 9 comments:
Thought this section expands on the previous guidelines, the information provided is scant. The evidence is limited for non-medical management in endometriosis, particularly, if we are talking about endometriosis and not pelvic pain. Though this did not stop the authors to make good practice points and other recommendations around surgical and hormonal treatments in the other sections.

We feel there is a missed opportunity for advocacy in women's health, providing advise about smoking cessation, balanced anti-inflammatory diet, avoiding elimination diets unless advised by a health professional, land-based exercise, etc. All having a link with improved outcomes in chronic pain conditions. The Cochrane review for non-surgical and non-pharmacological treatments does look at wider strategies than discussed in this guideline. This guideline can provide a great opportunity for introduction of multidisciplinary care for women with endometriosis and the more descriptive recommendations would facilitate this further. The lack of evidence in pelvic pain did not stop the authors making recommendations about 'neuromodulator' prescription extrapolated from wider chronic pain literature. Thus further extrapolation form chronic pain literature on management of pain symptoms in women with endometriosis or suspected endometriosis arguably can also be made

Question 10 comments: A timeframe for follow up can be suggested, including recommendation that for both the negative or positive laparoscopic findings follow up should be arranged and a plan for management of remaining symptoms is made. This is particularly important for symptoms such as pain and infertility. It should be the responsibility of the treating specialist to refer the patient to appropriate services/specialists if they have not achieved an improvement in symptoms after offering their services.

Comment on question 11:
There is limited discussion about recommendations in this GDG.

At the bottom of the chart it states ** offer hormonal treatment or laparoscopy to patient (including adolescents). This is counter to all advice from all paediatric and adolescent trained gynaecologists (and the input from ANZSPAG). It is also counter to the advice that the endoscopic surgeons give, that there should be one laparoscopy not multiple in a woman's life. There are studies that have demonstrated that the younger you are at first laparoscopy the more likely you are to have another.

Comments from question 8 would also be relevant:
We are somewhat startled to see that there is no examination of the evidence for the efficacy of surgery/outcomes following surgery. There is a question pertaining to it, but

the answer only really addresses excision vs ablation. It would be very important for this evidence to be properly appraised in the guideline.

A key question for the guideline group to explore in developing this is "who would benefit from surgery"- what factors can be identified which predict benefit or harm from surgical intervention and how can this be practically screened for in clinical practice.

Comment on question 12:
Agree for conditional recommendations and disagree when it comes to good practice points

The available evidence has been given considerable attention when offering recommendations and this is outlined under each conditional recommendation.

It would be useful to discuss the level of evidence for good practice statement points. It is not apparent in the summary and foreword or the ‘how to read this guideline’ section the reasons behind the ‘good practice statement’ points and any evidence or consensus to form these.

The Australian living guidelines are targeting a wide audience and thus not having an explanation of the level of evidence for the ‘good practice points’ can be confusing and even misleading. For example when a trial of opioids or 3-months course of NSAIDs is suggested (p 17 - points 26-29). The 'neuromodulator' guidelines consists of ‘Good Practice Statements’ only with no level of evidence listed and may be interpreted as prescriptive guideline while lacking evidence all together.

Comment on question 13:
The flow-charts like the one in this GDG are often found displayed around registrar rooms/clinical spaces/powerpoint slides and many other places where it is seen and taken for a gospel by both clinical staff, junior doctors and patients. It should be something that is loud and clear and very effective, some work is still required to achieve this and to ensure that inappropriate suggestions such as eg TV USS in adolescence and history of sexual trauma do not appear as the only way forward.

The flow chart is challenging for adolescent group. It suggests that TV USS should be offered to adolescents. This is against the established practice. I would also suggest that use of TV USS is highly challenging and triggering in anyone with sexual assault and developmental trauma history and an alternative imaging modality such as MRI must be offered and discussed.

At the bottom of the chart it states ** offer hormonal treatment or laparoscopy to patient (including adolescents). This is counter to all advice from all paediatric and adolescent trained gynaecologists (and the input from ANZSPAG). It is also counter to the advice that the endoscopic surgeons give, that there should be one laparoscopy not

multiple in a woman's life. There are studies that have demonstrated that the younger you are at first laparoscopy the more likely you are to have another.

We suggest change of 'opiates' to opioids in the chart and call them 'morphine like medications' rather than morphine containing (only Morphine in its different preparations such eg MS Contin contain morphine; oxycodone, tramadol, buprenorphine and all other opioids do not contain morphine).

The referral to MDT pain management team must be discussed and offered to all women with diagnosis of chronic pelvic pain with or without endometriosis. Leaving this as a last resort box at the bottom of the chart, robs 50% of women with chronic pelvic pain (those who unfortunately may have endometriosis) from having their symptoms of pain addressed in evidence-based fashion.

It would be helpful to have the 'signs and symptoms of endometriosis' included in the flow-chart together with their management, ie early management of bowel dysfunction, bladder irritability, sleep and mood disorders.

A separate working group may be needed to improve the standard of the flow chart or we would advocate for its removal in the current form from the GDG.

Research directions comments:
all future research into endo should include these groups, or at least clearly state which their participants fall into. Perhaps with the addition of an "endo status unknown" group.

Higher risk populations/specific groups:

Transgender recommendations should be considered under a separate topic.

The authors should use an opportunity to call to call both the research and outcome gap for First Nations people when it comes to endometriosis/chronic pelvic pain outcomes. Trauma-informed culturally-safe care should be strongly recommended for this population with particular call for localising access to the multidisciplinary care for these teams in the community-based Aboriginal medical centres.