

Draft NICE decision aid on making a decision about endometriosis

Deadline for comments 5pm on Monday 12 January 2026. Submission by email to: PDA@nice.org.uk

Please read the [checklist](#) for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

We would like to hear your views on these questions:

1. How helpful do you think this decision aid will be in supporting discussions between healthcare professionals and patients, and relatives and carers as appropriate?
2. Is there anything you would add, delete or change about each of the sections?
3. What is your overall impression of the decision aid?

Organisation name	Royal College of General Practitioners
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	<u>None</u>
Name of person completing form:	Dr Adrian Hayter

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Decision aid for endometriosis

Question	Comments: Do not paste other tables into this table because your comments could get lost – type directly into this table.
1. How helpful do you think this decision aid will be in supporting discussions between healthcare professionals, patients, relatives and carers?	We consider the content of the decision aid to be helpful and relevant. However, from a general practice perspective, the PDF format may limit its usability. Many younger patients primarily access information on mobile devices, and PDFs can be difficult to read and navigate on smaller screens. In primary care, documents are often shared electronically via clinical systems, which further highlights this issue. We suggest that the information would be more accessible and effective if it were available as an interactive web-based resource, ideally hosted on the NHS.uk website.
2a. Is there anything you would add, delete or change about the following section: What is this document?	No changes are suggested.
2b. Is there anything you would add, delete or change about the following section: 1. What is endometriosis?	We suggest that the visual elements in this section could be improved. The yellow areas on the diagram are not sufficiently eye-catching and may be difficult for patients to interpret. We recommend reordering the list of symptoms to begin with heavy periods, followed by severe period pain that interferes with normal daily activities. Additional symptoms could be included, particularly digestive or IBS-type symptoms such as bloating, constipation and diarrhoea. We also suggest expanding the information on timing, for example by stating that endometriosis can be diagnosed from the onset of periods at puberty through to menopause, and that it can affect anyone who has or has had a womb.
2c. Is there anything you would add, delete or change about the following section: 2. What do I need to think about?	We suggest moving the statement “There is no cure for endometriosis. Medicines and surgery can help to control symptoms. Your symptoms and endometriosis may return after treatment. This is called recurrent endometriosis” earlier in the document, potentially within the “What is endometriosis?” section, as this is a key concept that may help frame patient expectations from the outset.

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2d. Is there anything you would add, delete or change about the following section: 3. Diagnosis: what are my options?	Do not paste other tables into this table because your comments could get lost – type directly into this table. We recommend making it clearer that the diagnostic process often begins in general practice. GPs can undertake initial assessment and arrange baseline investigations, including ultrasound scanning, but referral to specialist care is required for MRI and further diagnostic testing. Clear expectation-setting at this stage is important for patients who are beginning to explore their symptoms in primary care.
2e. Is there anything you would add, delete or change about the following section: 4. Non-surgical treatment	We suggest clarifying that a range of treatment options can be offered and initiated in general practice, including symptom management without a formal diagnosis of endometriosis. This reflects current practice and supports timely symptom control. It would be helpful to explain that some pain relief medicines, such as NSAIDs, can also reduce heavy menstrual bleeding as well as pain, and may therefore be recommended for this dual benefit. We also suggest distinguishing clearly between non-hormonal and hormonal options. For non-hormonal treatments, it may be helpful to explain that these are often taken only during periods, which can be preferable for people who do not wish to take daily medication, although they may not control symptoms throughout the cycle. It should also be noted that NSAIDs may be contraindicated in people with asthma or other conditions, and that paracetamol and ibuprofen can be purchased without prescription. For hormonal treatments, it should be made explicit that these options are not appropriate for people who are trying to conceive. We suggest that the side effects of GnRH analogues would be clearer if presented as a bulleted list. We also recommend including adjuvant pain management and non-pharmacological strategies, such as pain management approaches (including TENS, yoga, relaxation techniques and acupuncture), physiotherapy, nutritional approaches, lifestyle measures (including exercise, diet and alcohol reduction), and psychological support such as CBT, pacing and mindfulness. Finally, it would be helpful to state explicitly that the aim of pain management is often self-management to improve quality of life, rather than complete elimination of pain.

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2f. Is there anything you would add, delete or change about the following section: 5. Surgical treatment	We suggest that the section beginning “having surgery will not cure endometriosis” would benefit from clearer formatting. This statement could be presented as a bold heading rather than embedded within a paragraph. A visual diagram, similar to those used in other NICE decision aids such as the Heavy Menstrual Bleeding aid, could also help patients understand the likelihood of symptom recurrence following surgery.
2g. Is there anything you would add, delete or change about the following section: 6. What’s important to you?	No substantive changes are suggested. However, from a general practice perspective, this section may be more useful if it were presented on a single A4 page to facilitate discussion during consultations. We particularly welcome the “my priorities right now” section, which would support shared decision-making and management planning.
2h. Is there anything you would add, delete or change about the following section: 7. Making a decision	No changes are suggested.
2e. Is there anything you would add, delete or change about the following section: 8. How this decision aid was produced	No changes are suggested.
3. What is your overall impression of the decision aid?	We consider this to be a good starting point, but believe further refinement is needed for it to become a truly valuable tool in general practice. It is unclear whether the decision aid is primarily intended for use in gynaecology clinics with patients who already have a confirmed diagnosis, or whether it is also meant to support discussions in primary care, where the diagnostic process usually begins. If it is intended for use in general practice, further development and input from GPs would be beneficial to ensure it aligns with primary care workflows and patient needs.

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Checklist for submitting comments:

- Use this comment form and submit it as a Word document (**not a PDF**).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Do not include any confidential information or any medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use.
- For copyright reasons, comment forms must not include attachments such as research articles, letters or leaflets. Any comment forms that include such attachments will be deleted without being read.
- We are seeking comments on the draft decision aid only; we are not able to accept any comments about the published NICE guideline on endometriosis (NG73, 2017). The decision aid does not amend or update the NICE guideline in any way.
- We do not intend to provide formal responses to comments received but we will take all comments you provide carefully into account.