Endometriosis: diagnosis and management – diagnosing endometriosis

Consultation on draft guideline - Stakeholder comments table
28/03/2024 – 16/04/2024

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Association of Clinical Psychologists UK	General	General	The draft guidance as a whole is helpful for medical colleagues around diagnosis and treatment of endometriosis, however, we as an organisation feel that it misses a crucial aspect of care for patients struggling with this condition. Endometriosis is a highly debilitating condition where diagnosis can take a number of years, and often results in patients experiencing psychological distress. Psychological interventions can improve quality of life for endometriosis patients, in spite of persistent physical symptoms such as pain (see Hansen et al., 2023 - Psychological interventions improve quality of life despite persistent pain in endometriosis: results of a 3-armed randomized controlled trial | Quality of Life Research (springer.com)). We strongly advise referral to appropriate psychological services for patients with endometriosis who are also experiencing psychological distress, and would welcome the inclusion of this in the guidance. These guidelines are incomplete due to the lack of consideration given to psychological approaches to treating patients with endometriosis.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate psychological interventions or support. However, it is recognised that psychological support for people with endometriosis may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Association of Clinical Psychologists UK	Table	15	Psychology is also notably absent in the recommendations for specialist endometriosis services. Again, as this condition causes considerable	Thank you for your comment. The composition of the specialist endometriosis services (endometriosis centres) is covered in the earlier

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			psychological distress, psychological intervention should be offered where needed. Integrated psychological support within medical MDTs has evidence-based positive impacts on outcomes such as reduced pain following surgery, optimisation of medications, improved adjustment post-diagnosis, optimisation of self-management. In anticipation of there being service users on this guideline update, we hope that these comments encourage discussion and consideration of why we should not be undertaking any medically-based interventions or treatment approaches without also considering the psychological impact and sequalae. This may well have been considered within the guideline discussion, but has not been recorded and as such the lack of psychological recommendations is striking.	section of the guideline 1.1 Organisation of care. This section was not within the scope of this focused update so it was not possible to consider the evidence for psychological support. However, it is recognised that psychological support may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Besins Healthcare UK Limited	Table	08	Consider including Dienogest in the hormonal section as it is a licenced medicine for Endometriosis	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate treatments, and so this section of the guideline has not been updated. However, it is recognised that this section may need updating and so this has been passed to the NICE surveillance team for consideration when future updates are planned.

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Besins Healthcare UK Limited	Table	10	In addition if a women has been diagnosed with Endometriosis and is waiting for surgery, options for treatment in the interim can be suggested e.g. Dienogest, GnRH may be beneficial prior to surgery	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate treatments, and so this section of the guideline has not been updated. However, it is recognised that this section may need updating and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Besins Healthcare UK Limited	Table	16	Consider addition of patients who may want to get pregnant for referral to secondary care teams/fertility etc.	Thank you for your comment. This section of the guideline 1.11 on Management if fertility is a priority' already covers the link with fertility services so this has not been added to the diagnosis and referral section of the guideline.
British Medical Ultrasound Society	Table	01	1.3.2 Yes, it is very good to raise awareness that endometriosis might run in families	Thank you for your comment.
British Medical Ultrasound Society	Table	1.5.3	Yes agree that TA should be offered with TV cannot be performed. Suggested rephrasing in line with BMUS TV eligibility guidelines. 'If a person declines a transvaginal scan or is ineligible to be offered one, consider a transabdominal ultrasound scan of the pelvis.' At the moment, the original statement puts the onus on the GP to determine if TVUS is appropriate or not. If it could be rephrased to be more inclusive due to the fact specific wording changes from the BMUS TV guidance	Thank you for your comment. This recommendation has been amended as you suggest to clarify that the reasons for not carrying out a transvaginal ultrasound may be because the woman or person with endometriosis does not wish to have this internal scan or if there are other reasons which mean it is not suitable for the person.

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			is transforming patient gynae scans for the better, because they are getting the TVUS they need, but in other departments it is still the sonographer who decides whether a person should or shouldn't be offered a TVUS. Ideally, healthcare professionals like GPs and sonographers should be discouraged from imposing on patients their own views. This is an important factor to consider.	
British Medical Ultrasound Society	Table	10	1.5 Yes I agree that ultrasound, initial treatment and referral can happen in parallel	Thank you for your comment.
British Medical Ultrasound Society	Table	11	1.5.1 Yes – but I would add the words in capitals: 'identify OVARIAN endometrioma and Deep Endometriosis involving the LIGAMENTS, bowel, bladder or ureter' Implementing the guidance that patients should now be OFFERED a scan (rather than one being considered) may increase the number of Pelvic Ultrasound scans being requested, despite the committee's view that it probably won't… But just as important as the number of scans being requested, is the quality of the scans being performed… <u>'Non-specialist sonographers'</u> need to have additional training in how to diagnose endometriosis, at the very least they need to implement the 'Sliding Sign' (REF	Thank you for your comment. The committee have amended the wording to state that deep endometriosis includes that involving the bowel, bladder or ureter, but is not limited to that. The committee considered that most women or people with endometriosis would receive an ultrasound scan at some point during the investigation of their symptoms and so the change to the recommendations may move this scan earlier in the diagnostic workup but not necessarily lead to additional scans. Thank you for highlighting the systematic review by Alcazar et al. We have checked this reference but it does not meet the criteria set out in the protocol of this review as it evaluated the diagnostic accuracy of one particular diagnostic

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			https://pubmed.ncbi.nlm.nih.gov/35289968/ **Diagnostic accuracy of sliding sign for detecting pouch of Douglas obliteration and bowel involvement in women with suspected endometriosis: systematic review and meta-analysis / J L Alcazar et al2022)**) as becoming part of every routine pelvic ultrasound. Sonographers need to learn that endometriosis can mostly not be visualised on transabdominal ultrasound, so that if the scan has only been done transabdominally, then endometriosis cannot be excluded, and the report needs to state that clearly. <u>'Specialist sonographers'</u> need to undergo specialist training in how to diagnose pelvic endometriosis – this could be through an additional qualification eg a Postgraduate Diploma in Advanced Gynaecology Ultrasound (delivered by universities currently teaching the PgC in Gynaecology Ultrasound). Certainly the sonographers working in BSGE-accredited endometriosis centres should have undergone further training. The British Medical Ultrasound Society (BMUS) is in a good position to help write protocols for training and delivery of such educational modules.	feature (the sliding sign) on transvaginal ultrasound, so it has not been included. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation. Thank you for informing us about the development of 'Gynaecology Sonology'. It is hoped that this will further improve the early identification of endometriosis.

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			If no further training is offered, the risk is that more scans will be performed, but that they will not improve the detection of endometriosis. Also an endometriosis scan takes longer to perform than a routine gynaecology pelvic ultrasound and this needs to be taken into account when Departments plan their lists. If the sonographer does not have enough time to perform the scan, it may be falsely negative. The initial scan could be done by a Non-specialist sonographer', but then the scan should be repeated on a different list by an experienced 'Specialist sonographer', with more time allowed for the scan. It is also important to realise that many gynaecology scans are now being performed by Gynaecologists, and that the speciality of 'Gynaecology Sonology' (a gynaecologist who is a specialist in gynaecology ultrasound) is becoming more common, and that such staff also need to have undergone specific and advanced ultrasound training. This could be quality-assured by the Royal College of Obstetricians and gynaecologists together with the British Society of Gynaecological Endoscopy (RCOG and BSGE).	
British Medical Ultrasound Society	Table	13	1.5.3 Yes I agree – very important to stress that a normal scan should not delay a referral to gynaecology	Thank you for your comment.

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British Medical Ultrasound Society	Table	14	1.5.4 In 'Consider referring patients for 3 reasons', the text says OR – should this not be AND/OR?	Thank you for your comment. It is not NICE style to use AND/OR. If a woman or person had any of these factors they would require referral, and that would not change if they had 2 or more of them, so the 'and' is not strictly necessary.
British Medical Ultrasound Society	Table	20	1.5.9 Yes I agree – diagnose endo by pelvic MRI or specialist TV ultrasound	Thank you for your comment.
British Medical Ultrasound Society	Table	21	1.5.10 Yes it is essential that MRI should be interpreted by a radiologist specialised in endometriosis imaging	Thank you for your comment.
British Medical Ultrasound Society	Table	22	1.5.11 Yes I agree to consider laparoscopy when imaging is negative	Thank you for your comment.
British Medical Ultrasound Society	Table	23	1.5.12 Yes I agree – consider specialist TV-US or MRI before laparoscopy if DE is suspected	Thank you for your comment.
British Medical Ultrasound Society	Table	24	1.5.13 Yes the gynaecologist doing the laparoscopy should have training and skills in surgery for endometriosis – NICE might need to define to what level this training should have been evidenced/quality assured eg after consulting with the British Society of Gynaecological Endoscopy (BSGE).	Thank you for your comment. NICE guidelines do not usually define the exact levels of skills or training needed as this is often better described by professional bodies such as the BSGE, as you suggest.
British Medical Ultrasound Society	Table	26	1.5.15 Yes I agree that endometriosis would be unlikely if the laparoscopy is normal (but it is not impossible)- it	Thank you for your comment. An earlier recommendation already advises that a

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			depends on the skill of the operator, but that alternative management suggestions are valuable.	diagnostic laparoscopy should be carried out by someone with the necessary skills and training.
British Society of Lifestyle Medicine	General	General	We recommend that evidenced based lifestyle advice is mentioned either alongside the advised pharmacological measures from the outset. Within primary care GPs and other HCP can advise that using the pillars of lifestyle medicine around nutrition, physical activity, sleep, stress and relaxation and avoiding harmful substances may help patients manage their symptoms whilst awaiting investigations and diagnostic procedures. Sleep, nutrition and endometriosis. Links to relevant articles highlighting the importance of inclusion of lifestyle medicine (advice) for women from the outset; https://www.ejog.org/article/S0301-2115(23)00854-0/pdf https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7446064/ https://bmcwomenshealth.biomedcentral.com/articles/10.1186/s12905-020-01036-z	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate lifestyle interventions. However, it is recognised that lifestyle interventions may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Endometriosis Guidance and Information Resource UK	General	General	Further comments As with any consumer product, as this guideline ultimately is, we feel that there is only so much updating can be done with the passage of time before a new model needs to be designed. We feel that point has been reached and that the proposed updated guideline is confusing and incoherent in many respects and lacks	Thank you for your comment. This update was focused on 2 specific areas of the guideline (diagnosis and surgery when fertility is a priority) as this was where new evidence that might lead to a change in recommendations had been identified. As part of this update the committee recognised that certain sections of the guideline did not reflect the patient pathway and so some

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			continuity or cohesion. We feel that the whole guideline needs revisiting to incorporate all new guidelines and standards that affect it. In any event we would ask that additional consideration to be given to: 1) The production of a meaningful list of symptoms so that the guideline is effective in its purpose rather than the generic period-based list that doesn't represent reality, based on published evidence such as in ESHRE and RCOG publications who are stakeholders in this review. 2) Updating the endometriosis algorithm to reflect ESHRE recommendations to perform clinical examination and imaging as the initial treatment, with suspected severe endometriosis (pelvic signs, endometriomas/DIE/RVE on imaging) referred straight to specialist centres prior to empirical treatment or diagnostic laparoscopy, to identify deep disease early. 3) Updating of 1.1.3 once the NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), is final which requires that all hospital-based gynaecology services in endometriosis networks providing medical and surgical treatment for non-severe endometriosis, must have a named and	reordering was carried out. However, it is recognised that other sections of the guideline may require updating and the ones you have highlighted (points 1, 4, 5, and 7) will be passed to NICE surveillance team to consider when future updates are planned. In response to your second point, the recommendations have been updated and a new one added as part of the current update to advise that investigations and referral should be carried out at the same time as initial pharmacological treatment. The committee agreed that it was not appropriate to delay starting initial pharmacological treatment such as analgesics until after the person had been seen in a gynaecology or specialist centre as this may leave people in pain while on a waiting list to be seen. In response to your third point the guideline already includes details on the organisation of specialist endometriosis services which includes details of the personnel required, but it is recognised that more detailed information about the organisation of specialist services is included in the NHS service specification for

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			designated clinical lead for endometriosis with a special interest and expertise in the diagnosis and management of endometriosis who can perform minimal access surgery. 4) Updating of 1.1.3 to include 'a named healthcare professional with an interest in gynaecological imaging, including proficiency in assessing the uterine sliding sign'. 5) Updating of 1.1.4 once the NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), is final which requires that endometriosis centres must now include psychological and psychosexual counselling support, women's health physiotherapy, a paediatric gynaecologist and a member of staff from within the team nominated to support service users to navigate pathways and their patient experience. 6) Correction of all references to 'bowel, bladder and ureter' to 'deep infiltrating or rectovaginal endometriosis' or 'severe endometriosis' in line with the NHS England specification definition (1.5.1, 1.5.5, 1.7.1, 1.10.2, 1.10.4, 1.10.5, 1.11.1, 1.11.3, endometriosis algorithm) 7) Addition to 1.10.8 that if a hysterectomy/oophorectomy is indicated in women with	severe endometriosis so this has not been repeated in the guideline. In response to your sixth point, despite the fact that the current NHS service specification uses the term 'deep infiltrating' the committee agreed that this term was not widely used anymore as it has connotations with cancerous conditions and could cause undue stress to women and people with endometriosis. However, changes have been made to the recommendations which are part of this update to clarify that deep endometriosis may affect organs including (but not limited) to the bowel, bladder and ureter. In response to your eighth point, although this section of the guideline was not part of the update this small change to wording has been made to ensure consistency between the diagnostic and treatment laparoscopies. In response to your ninth point, the NICE use of more inclusive language is being rolled out across guidelines as they are updated. It is recognised that this may lead to some discrepancies within guidelines in the short term.

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			a history of severe endometriosis it must only be performed in a specialist endometriosis centre. 8) Addition to 1.10.3 to require recording of all endometriosis surgery by photographs and/or video and not just diagnostic laparoscopy. 9) Presumably all the many references to woman/women not part of the update will need amending to include 'people'.	
Endometriosis Guidance and Information Resource UK	Table		Endometriosis: Diagnosis and Management (NG73), Page 3, lines 1-5. It is recommended to be aware of family history when assessing signs and symptoms which may lead to earlier diagnosis. Whilst important, we consider the signs and symptoms are most crucial and in our view the list at 1.3.1 is substantially inadequate and outdated. We were not stakeholders at the November 2022 surveillance review so could not comment but understand that the decision as to whether updates were needed was based on completed questionnaires from just 5 topic experts and a patient group. It seems 2 of the former contributors thought no update was required; whether any of these experts were endometriosis specialists is not known but we feel this limited scope is concerning given the number of women in the UK the guideline affects (an estimated 1.3 million).	Thank you for your comment. The surveillance review in 2022 only identified that new evidence was likely to lead to changes in the recommendations for 2 sections of the guideline (diagnosis and treatment when fertility is a priority). The section of the guideline on signs and symptoms was not in the scope of this update. However, as you and other stakeholders have identified, there may be other sections of the guideline which require updating, including the list of signs and symptoms, and so this has been passed to the NICE surveillance team for consideration when future updates are planned. The NICE processes for surveillance include the use of topic expert advisors but we will pass your feedback on the amount of expert involvement to the NICE surveillance team.

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			The emphasis on period-related/cyclical symptoms gives the impression that endometriosis is a period-related menstrual health condition when it is not; endometriosis is a complex Reproductive Health disease. Whilst many will experience period-related symptoms, we believe it is essential that non-cyclical symptoms are at least equally recognised to diagnose early. The ESHRE guideline (2022) emphasises that all symptoms should be considered in a cyclical and non-cyclical context and includes symptoms of thoracic/diaphragmatic endometriosis, fatigue and notes non-cyclical symptoms and nausea have been identified as especially prevalent in adolescents, a crucially important sub-group when considering early diagnosis https://www.eshre.eu/Guideline/Endometriosis. As well as diagnosing endometriosis early, we believe it is essential to diagnose severe disease early. Non-cyclical symptoms (e.g. bowel/bladder related) and back/leg pain are well recognised and among the most prevalent in our members with severe disease. Whilst sciatic endometriosis does exist, the most common cause of back and leg pain is associated with uterosacral ligament (rectovaginal) disease in our members' experience but may be caused by referred neuropathic pain from pelvic nerves generally that arise in the sacral plexus, the source of the sciatic nerve.	

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			As well as the ESHRE guideline, RCOG's information sheet includes *'pain to the lower back, top of your legs and long-term fatigue'* https://www.rcog.org.uk/media/sojl5sif/endometriosis.pdf and Endo UK's list includes fatigue and back/leg pain https://www.endometriosis-uk.org/symptoms, all of whom are stakeholders in this review. It is unclear therefore why it wasn't considered appropriate and essential that the symptoms section was brought up to date and why these sources, especially the ESHRE guideline, were not consulted as evidence when the starting point on which effective diagnosis relies is the correct identification of symptoms. We consider this to be a significant issue and would request that the symptoms section be revisited if this updated guideline is to be effective. We do not consider the recommendation would be challenging to implement or have significant cost implementations.	
Endometriosis Guidance and Information Resource UK	Table	01	Endometriosis: Diagnosis and Management (NG73), Page 4, lines 1-3 and whole comment. The rationale for empirical treatment of suspected endometriosis without a diagnosis has historically been to avoid the risks of laparoscopy, but the diagnostic laparoscopy is no longer the gold standard (ESHRE 2022, 1), and with advances in non-invasive diagnostic approaches, especially imaging, ESHRE now recommends	Thank you for your comment. The committee were clear that women or people with endometriosis should receive pharmacological treatment (such as painkillers or hormonal treatments) to alleviate symptoms after clinical examination and while awaiting or undergoing scans and referral. A new recommendation has been added to the guideline to state that initial

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			combined clinical examination and imaging (TUS or MRI) as the first approach to identify endometriomas and deep disease early, before empirical medical treatment or referral to explore peritoneal disease (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis), https://www.eshre.eu/Guideline/Endometriosis. The ESHRE guideline has been a reference point for best clinical care in endometriosis for years (Oxford Academic, https://academic.oup.com/humrep/article/29/3/400/707776) and is endorsed by RCOG. Under 'Legislation, regulation and guidance', the final scope for the 2017 guideline advised that it would consider similar areas to the ESHRE guideline but in the context of NHS-commissioned healthcare, with consideration given to cost and clinical effectiveness. https://www.nice.org.uk/guidance/ng73/documents/endometriosis-final-scope2 We have been unable to find any reference to ESHRE in the scope or evidence documents for this update, but assume that the same 'Legislation, regulation and guidance' must necessarily apply. With that in mind, it's not clear why this update places pharmacological treatment for suspected endometriosis as the initial treatment for women with suspected endometriosis against ESHRE recommendations, between clinical	pharmacological treatment, ultrasound and referral can all take place in parallel. This means that women or people with suspected endometriosis based on symptoms and clinical examination would not be left untreated and with pain or other symptoms while awaiting an ultrasound scan or secondary care appointment. The committee did not advise that women or people should be left undiagnosed. The section on diagnosis and referral has been amended to advise that people should be referred if they have severe, persistent or recurrent symptoms, pelvic signs or if they have endometriomas or deep endometriosis. While the patient pathway is therefore laid out slightly differently to the one presented by ESHRE, the NICE pathway does not suggest that people with suspected deep endometriosis should just be treated with pharmacological treatment and no further action taken. The ESHRE guideline also recommends that empirical treatment with hormones is used in conjunction with imaging and this therefore is in agreement with the NICE recommendations. You are correct that NICE will take into account robust guidelines developed by other organisations such as ESHRE when developing its own guidance, but the evidence review for this update considered the diagnostic accuracy

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			exam to identify any reduced pelvic mobility/nodularity (essentially evidence of severe disease) and imaging, which doesn't seem logical. Medical treatment is not appropriate for suspected severe disease, and we consider the ESHRE algorithm should be applied with clinical exam and imaging being undertaken at the outset, with any signs of endometriosis referred for further diagnostic tests to explore the presence and extent of DE and endometriomas by further advanced imaging, proceeding to treatment in an endo centre, before consideration of pharmacological treatment. We consider this to be vital, since once placed on medical treatment any symptoms suggestive of severe disease can be masked and the opportunity lost to identify it early, which is what we believe the new ESHRE pathway aims to do. Those presenting with suspected endometriosis are likely to have already been given any number of medical treatments anyway, often over many years, including contraceptives as adolescents for primary dysmenorrhea which is a recognised risk factor for the development of severe disease down the line, and we see this almost routinely with our members (Chapron et al., 2100, ESHRE Guideline 2013). Many such members are told by their GPs that they cannot have scans or referral unless agreeing to yet more medical treatments that have already proved ineffective, which	of ultrasound and MRI scans so there would be no specific reason to refer to the ESHRE guidelines in the evidence review. The NICE guideline is clear that if a trial of initial pain relief is unsuccessful, not tolerated or contraindicated then a referral is advised, so the guidelines do not suggest that people should be trialled on multiple courses of pharmacological therapy.

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			has no justification in our view, and we feel the placement of the new section on initial pharmacological treatment for suspected endometriosis will just perpetuate what we already suspect to be at the root of long diagnostic delays – the masking of symptoms by hormonal manipulation without a diagnosis, with women only returning to their GP when symptoms become unmanageable again to find that severe disease has progressed/developed, when it could have been avoided or caught early with timely appropriate intervention at the first presentation. The existing guideline places diagnosis first, prior to pain management; the guideline is entitled endometriosis 'Diagnosis and management', one before the other. We cannot agree to the placement of this section on 'initial pharmacological treatment' as the first step in the pathway, prior to diagnosis and contrary to the ESHRE recommendation, as we believe it to be out of date, not backed by evidence and likely to continue to prolong diagnostic delays by masking progression of disease. It appears that the only valid reason for going against the ESHRE recommendation to diagnose deep disease early, prior to pharmacological treatment, would be based on consideration of cost and/or clinical effectiveness as stated in the original scope. We believe it fails on both counts since we do not consider that it can benefit women to develop undiagnosed	

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			severe disease with symptoms masked and feel it must be far more costly to treat severe disease than to prevent it from developing. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it, due to being contrary to ESHRE recommendations.	
Endometriosis Guidance and Information Resource UK	Table	05	Endometriosis: Diagnosis and Management (NG73), Page 6, lines 1-2. It is of note that pharmacological pain management in the current guideline comes after diagnosis and not before, thus those with identified or suspected severe disease would have already been referred on to specialist centres. Under neuromodulators and neuropathic pain treatments, the link is given to the NICE guideline on neuropathic pain (CG173). We do not feel this to be appropriate. The linked guideline is for neuropathic pain management in non-specialist settings for such conditions as neuralgia, shingles and diabetes. Given the placement of this section under initial pharmacological treatment of suspected endometriosis, we feel that there can be no place for management of neuropathic pain in primary and non-specialist secondary care for those suspected of having endometriosis. There is a separate guideline (NG59) for low back pain and sciatica, not linked; these neuropathic symptoms are most usually associated with	Thank you for your comment. A new recommendation has been added to the guideline to state that initial pharmacological treatment, ultrasound and referral can all take place in parallel. This means that women or people with suspected endometriosis based on symptoms and clinical examination would not be left untreated and with pain or other symptoms while awaiting an ultrasound scan or a secondary care appointment. The committee were aware that many conditions leading to neuropathic pain are managed in non-specialist or primary care and this would include endometriosis. The neuropathic pain guideline includes advice to consider referral to specialist pain services or condition-specific services for severe pain, pain affecting lifestyle or daily activities, or if health has deteriorated, as well as

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			endometriosis. However, although these are very important symptoms, they are excluded from the symptoms list so why treatment of neuropathic pain is included under initial management of suspected endometriosis when not recognised as a symptom is unclear. Such symptoms are usually indicative of severe disease (pelvic nerve damage/compression from endometriosis fibrosis or surgical damage) and it would seem to be far more useful to acknowledge these symptoms to aid swift identification of deep disease, rather than giving guidance on how to mask such pain in primary care settings which we believe can only feed into the long diagnostic delays. We feel that treatment of neuropathic pain should only be considered in specialist endometriosis centre settings as part of specialist pain management services included in multidisciplinary teams, after diagnosis and in the context of treatment decisions for known disease. We consider that empirical pharmacological treatment options for those with no signs of endometriosis after clinical exam/imaging, not wishing for a diagnostic laparoscopy, should be limited to simple analgesics and hormone preparations such as the COC/progestins, and that severe, complex pain presentations such as neuropathic pain in the presence of other endometriosis symptoms should be referred for specialist assessment by advanced imaging and input from specialist pain	containing a link to the NICE guideline on low back pain or sciatica. The signs and symptoms of endometriosis were not within the scope of this update and so no evidence review was carried out. However, as you and other stakeholders have identified, there may be gaps in the completeness of the guideline, including the list of signs and symptoms, and so this has been passed to the NICE surveillance team for consideration when future updates are planned.

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			management teams and not treated by GPs. The ESHRE guideline (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis) confirms that empirical treatment is limited to combined hormonal contraception or progestogens, and not complex pain medications such as neuromodulators and neuropathic pain treatments. https://www.eshre.eu/Guideline/Endometriosis. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose the use of neuromodulators and neuropathic pain treatments as a first line treatment of suspected endometriosis in primary/secondary care settings.	
Endometriosis Guidance and Information Resource UK	Table	06	Endometriosis: Diagnosis and Management (NG73), Page 6, lines 4-6. A link is given to a 'patient decision aid on hormonal treatment for endometriosis'. We believe this is out of date and contains inaccuracies. It is said that it '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 painkillers'. The ESHRE guideline 2022 (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis) recommends that medical treatment to suppress symptoms should not be the first step in the pathway. https://www.eshre.eu/Guideline/Endometriosis.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate treatments. However, NICE is working separately on an update of the patient decision aid for endometriosis to take into account recent work on the guideline. This will be published separately and will not be available at the same time as the publication of this update. The guideline already advises that women or people whose endometriosis does not respond

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			It is well recognised that this can lead to masking of progression of disease (Chapron et al., 2100, ESHRE Guideline 2013) and the first recommended step is clinical exam and imaging to identify deep disease early, with empirical medical treatment/diagnostic laparoscopy following if there is no evidence of severe disease. In any event a majority of women with suspected endometriosis are likely to have already been on medical treatment, often for years, and only seek help when it is no longer is effective, often indicating progression to severe disease. It is said that endometriosis cells bleed during a period, like the endometrium which 'creates inflammation, scarring and may cause organs and tissues to stick together – these effects cause pain. The aim of hormone treatment is to reduce or stop this bleeding so that these effects are reduced or do not happen'. This simplistic view of endometriosis is not supported by evidence and in our view is at the root of the diagnostic delays – presenting endometriosis as a period condition, with symptoms largely period-related, with a belief that hormone medications 'treat' endometriosis and stop it growing. It seems well understood by experts that hormone medications treat endometriosis pain not the disease, which can continue to progress in those on hormone suppression and after menopause	to pharmacological treatment should be referred for further investigations and treatment so no changes to the recommendations have been made. Thank you for the information on the aetiology of endometriosis.

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			ESHRE, 2022, VI.2. https://www.eshre.eu/Guideline/Endometriosis. A period is triggered when the corpus luteum dies and the spiral blood vessels supplying the endometrium are cut off causing the endometrium to die and be shed as blood/menstrual debris. The spiral arteries are unique in the human body in their ability to degenerate/regenerate under hormonal influences. Endometriosis exists in ectopic locations supplied by blood vessels via angiogenesis from the general circulation. It's blood supply is not cut off each month. The inflammatory process of endometriosis is via the PGE2-aromatase-oestradiol pathway within endometriosis cells and is self-sustaining regardless of the menstrual cycle or hormone manipulation. Post menopausal endometriosis is treated medically with aromatase inhibitors which aims to interrupt this intracellular process. Bleeding associated with endometriosis is thought to be due to the withdrawal of progesterone prior to a period triggering systemic and local peritoneal inflammation, potentially causing new blood vessels to rupture. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose the	

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			inclusion of this link as we believe it to be out of date and contrary to current evidence.	
Endometriosis Guidance and Information Resource UK	Table	10	Endometriosis: Diagnosis and Management (NG73), Page 7, lines 7-10, Page 8, lines 1-3. A new entry is made at 1.5 recommending that 'additional investigations such as ultrasound and referral (if necessary) can be carried out in parallel with each other, and in conjunction with initial pharmacological treatment' but we feel this reads very much as an afterthought. Section 1.4 on initial pharmacological treatment is titled in bold and two pages long; we believe GPs will accept this as the appropriate initial treatment and continue treating women medically and if they respond to such treatment, we feel that GPs are unlikely to read further and see what we feel is a somewhat confusing and misplaced comment. Even if they do, it's not clear what is meant by 'additional investigations' and 'if necessary' since at this point the only investigation to be offered is a clinical exam to identify any signs of deep endometriosis (without any context or follow through given) followed by the long section on initial pharmacological treatment. So, this seems to be saying that if pharmacological treatment suppresses symptoms, then no further investigations would be considered 'necessary', being the traditional treatment that we believe leads to such long delays by masking progression to what is often severe disease	Thank you for your comment. The committee decided that women or people presenting with symptoms of endometriosis should, after a history and examination has been taken (as described in section 1.3) be offered medication to control their symptoms (as described in section 1.4) but that further investigations and referral may be needed (as described in section 1.5). The committee agreed this order of the sections in the guideline represented the patient pathway more closely than the previous order. The section on diagnosis and referral (section 1.5) will apply to the majority of women and people with suspected or confirmed endometriosis, but there may be people whose symptoms resolve with adequate analgesia or hormonal treatment, and who do not wish to have further investigations such as a transvaginal ultrasound or to be referred. The aim of the guideline is to make the most effective use of gynaecology services, referring those who need to be referred, but not overwhelming services by automatically referring all women or people with endometriosis. A new recommendation has been added to clarify that while the guideline

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			which could have been prevented by early diagnostic interventions. Explanatory notes are added under rationale and impact to emphasise that initial pharmacological treatment, a non-specialist ultrasound and referral can happen in parallel rather than sequentially so that the overall pathway of care is more timely. But it doesn't appear to emphasise anything and leaves the GP to decide what is necessary. Many women given long standing medical treatment gain significant relief and won't go back to a doctor for any additional investigations until it is no longer effective and severe disease has developed. The ESHRE guideline 2022 seems clear that the key to timely diagnosis is the identification of deep disease through clinical exam and imaging, before empirical medical treatment and does not recommend that these happen in parallel (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis). https://www.eshre.eu/Guideline/Endometriosis. We feel that the switching of diagnosis/referral with initial pharmacological treatment of suspected endometriosis as the first step in the pathway until such treatment is no longer effective will be catastrophic for women and perpetuate the long delays in diagnosis. We consider the ESHRE recommendations to be straightforward, logical, evidence-based, cost effective	lays out a suggested patient pathway it does not mean that each stage has to be completed before the next stage can start (for example all possible pharmacological options do not have to be tried before an ultrasound can be requested). The committee agreed this was not different from the ESHRE guidelines, as any findings suggesting anything other than mild endometriosis that responds to treatment are likely to lead to a referral.

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			and in the interest of women and early diagnosis. 1) Clinical exam and ultrasound aimed at identifying deep disease, 2) Masses found on clinical examination, endometriomas and/or deep disease found on imaging referred straight to an endometriosis centre, 3) Negative clinical exam/imaging - empirical treatment/laparoscopy to relieve symptoms or investigate peritoneal disease according to individual preference, with it being acknowledged that many if not most will have already been on medical treatment without success or have found it to be no longer effective rendering further empirical treatment as a first option inappropriate and potentially harmful without the above investigations undertaken first. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it and find it incoherent and muddled.	
Endometriosis Guidance and Information Resource UK	Table	11	Endometriosis: Diagnosis and Management (NG73), Page 8 lines 5-29. It is said that GPs should offer TUS to all women and people with suspected endometriosis. This entry seems somewhat confused and back to front, as it has already been advised to give initial pharmacological treatment and only investigate further with ultrasound/referral if considered necessary, with the GP left to decide what is 'necessary'. Three pages in they are effectively being told what they should have	Thank you for your comment. The committee agreed that women or people presenting with symptoms of endometriosis should be offered pain relief and other pharmacological treatments to alleviate their symptoms, and that all women or people should be offered an ultrasound, while referral (if necessary) was ongoing. The committee were aware from their own experience that in many cases of mild

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			done first and if this had been in what we consider the right place at 1.4, this would have immediately followed the pelvic examination and accorded with ESHRE recommendations (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis), https://www.eshre.eu/Guideline/Endometriosis. We doubt if any GP will pursue further investigations if the woman's symptoms have been resolved with medical treatment, after being told this is the initial treatment and she is unlikely to go back anyway until symptoms are no longer resolved, with severe disease potentially having developed. The ESHRE guideline 2022 seems clear in its recommendation to carry out clinical exam/imaging before pharmacological treatment to identify deep disease early and not when medical treatment no longer eases symptoms. It is well recognised that this is likely a fundamental reason for the long diagnostic delays – leaving women on medical treatment without a diagnosis. It is said that GPs should offer TUS, even if pelvic or abdominal exam is normal. This is the first mention of pelvic and abdominal examination since 1.3.4, three pages earlier, when it was implied that any clinical findings should initially be treated pharmacologically when we consider the ultrasound should have been done at that time. This seems to suggest that GPs should offer an ultrasound if pelvic or abdominal	endometriosis, if symptoms resolve, no further treatment is necessary, and referral may not be necessary, so not all people with endometriosis will require a referral. The aim of the guideline is to make the most effective use of gynaecology services, referring those who need to be referred, but not overwhelming services by automatically referring all women or people with endometriosis. The reasons for referral are explained in the subsequent recommendations (1.5.5 onwards) and so a cross-referral to this has been added from this statement. You are correct that if initial treatment is not successful women or people will be referred, but as the initial pharmacological treatment is meant to be a trial of, for example, 3 months, this should not lead to excessive delays in referral. The committee agreed that an ultrasound was necessary before referral as it may indicate other pathology that is a cause for the symptoms, and so would allow for an appropriate referral to be made or will help determine that a referral is necessary for

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			examination is abnormal (i.e. deep endometriosis is suspected) when the ESHRE algorithm is clear that any such signs from either pelvic examination or initial imaging should be referred for further diagnostic steps to explore the presence and extent of DE and endometriomas which can only be done in a specialist centre. There appears to be no value in offering a non-specialist ultrasound in such a situation since basic sonographers are not generally trained to look beyond the reproductive organs (it is potluck whether they might) and this can delay the correct onward pathway to specialist care. The draft updated NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which is laid down in legislation and currently published to stakeholders for feedback prior to wider consultation, is clear that care providers must always refer suspected severe endometriosis to specialist centres and 'abdominal masses and pelvic signs, such as reduced organ mobility and enlargement, tender nodularity in the posterior vaginal fornix and visible vaginal endometriotic lesions' as described at 1.3.4, all clearly represent suspected severe endometriosis. Under rationale for change, it is said that the aim of this non-specialist ultrasound is to identify endometriomas and deep endometriosis involving the bowel, bladder and ureters. It seems that reasonably sized	suspected endometriosis, as defined in the recommendations. The need to refer if there are pelvic signs of endometriosis is already included in the recommendation on when to refer. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation. The guideline already recommends that any woman or person with symptoms or signs showing suspected deep endometriosis should be referred and, as you state, these are already listed in the recommendations in section 1.3. The definition of deep endometriosis has been expanded to indicate that it includes endometriosis affecting the bowel, bladder or ureters, but is not limited to these organs only.

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			endometriomas are relatively easy for the more general sonographers to identify but assessment of the bladder, bowel and ureters requires great specialist expertise usually only available in specialist centres, being mostly retroperitoneal, and these presentations are relatively rare. Bowel endometriosis only affects up to 12% of those with endometriosis (International journal of women's health, 2013/ AJG Journal, 2022, Chang et al) while urinary tract disease is usually reported as affecting only around 1% of cases. On the contrary, rectovaginal disease is by far the most common and complex presentation of severe endometriosis, involving the rectum/sigmoid being stuck to the cervix/vagina (obliterated POD) with the US ligaments usually involved, affecting up to 37% (International journal of women's health, 2013/ AJG Journal, 2022, Chang et al), and being what the BSGE accredited centres were set up for. Furthermore, it is rectovaginal endometriosis that is associated with endometriomas and the presence of endometriomas has been reported as being a marker for deep rectovaginal endometriosis (Redwine DB, Fertil Steril, 1999; 72: 310-315, Chapron et al, Fertil Steril 2009; 92: 453-457. Therefore, it's not clear why deep disease affecting the bowel, bladder and ureter has been singled out, with the most significant presentation, rectovaginal disease, excluded. We believe this is crucially important since the hallmark of rectovaginal endometriosis on ultrasound is a	

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			negative sliding sign (the cervix/uterus being stuck to the bowel indicating an obliterated pouch of Douglas) and is easy to learn https://obgyn.onlinelibrary.wiley.com/doi/10.1002/uog.12431. We believe a proficiency in assessment of the sliding sign to be fundamental to the early identification of severe disease which we believe can be achieved at the GP referral stage, if an appropriately trained sonographer is identified. To this end we feel the following comment would be more appropriate 'identify endometriomas and rectovaginal endometriosis by assessment of the sliding sign'. We would like to see a sonographer with this skill as a minimum to be available in the endometriosis networks, as well as the named gynaecologist with a special interest in endometriosis as proposed by draft updated NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which is laid down in legislation and currently published to stakeholders for feedback prior to wider consultation. We have suggested that all endometriosis networks have access to such a trained and named sonographer for an initial scan since we believe that identifying a negative sliding sign indicative of rectovaginal endometriosis, and correlating with the presence of endometriomas when appropriate, would revolutionise early diagnosis.	

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			We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it, finding it inaccurate, incoherent and muddled.	
Endometriosis Guidance and Information Resource UK	Table	12	Endometriosis: Diagnosis and Management (NG73), Page 10, lines 1-4. It is recommended that if a transvaginal scan is not appropriate a transabdominal ultrasound should be considered. We do not consider this sufficient. Many such people will be adolescents and the ESHRE guideline 2022, V.I.e, recommends that where TUS is inappropriate, MRI, transabdominal, transperineal and transrectal scan may be considered https://www.eshre.eu/Guideline/Endometriosis. The time between onset of symptoms and diagnosing endometriosis is reported to be more than 12 years if onset was in adolescence (Geysenbergh, et al. 2017) so it seems likely that many ultimately receiving a diagnosis probably had it from adolescence. Some authors state that that adolescent endometriosis may be more progressive than in adults (ESHRE, 2022, V.I.c) and it seems clear that diagnosing disease early in adolescents is crucial to addressing diagnostic delays. We believe that denying adolescents appropriate imaging (MRI) based on not yet being sexually active to be discriminatory. The draft updated NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which	Thank you for your comment. The committee were aware that an MRI scan cannot be requested directly by general practice and therefore this would not be an available alternative for ultrasound scans requested outside secondary care. The committee agreed that even in secondary care it would be preferable to carry out an ultrasound first (to look for endometriomas and other pathology) before proceeding to an MRI scan. There was very little evidence identified for other routes of ultrasound such as transperineal or transrectal, and these may also be unacceptable to people, so the committee chose not to recommend them as alternatives. There is a separate recommendation relating to women or young people who are 17 years or under with suspected or confirmed endometriosis and which advises that they should all be referred to a paediatric and adolescent gynaecology service or a specialist endometriosis service, so this is already in-line with the NHS service specification.

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			is laid down in legislation and currently published to stakeholders for feedback prior to wider consultation, requires that care providers must all refer confirmed or suspected severe endometriosis direct to a specialist endometriosis centre, and this will now include adolescents with severe or suspected severe disease. So we believe that affording them appropriate diagnostic facilities to be essential and their fundamental right. Likewise, we believe the same applies to anyone for whom transvaginal ultrasound is not appropriate. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it due to considering it discriminatory for some subgroups with suspected endometriosis.	
Endometriosis Guidance and Information Resource UK	Table	14	Endometriosis: Diagnosis and Management (NG73), Page 10, lines 24-25. It is advised to consider referring women or people to a gynaecology service if they have pelvic signs of endometriosis. We assume that 'pelvic signs' refers to 'abdominal masses and pelvic signs, such as reduced organ mobility and enlargement, tender nodularity in the posterior vaginal fornix and visible vaginal endometriotic lesions' as described at 1.3.4. following abdominal and pelvic examination. Such 'signs' represent suspected severe endometriosis and the ESHRE guideline algorithm (Page 187, Annex	Thank you for your comment. The committee agreed that any woman or person with pelvic signs should be referred to a gynaecology service for further investigation and management as these signs may be due to other conditions as well as endometriosis, unless there is suspicion of deep endometriosis (in which case the recommendations already advise referral to a specialist endometriosis service). This is therefore in accordance with the NHS service specification.

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			5: Flowcharts, Diagnosis of endometriosis) https://www.eshre.eu/Guideline/Endometriosis advises that these cases should be referred for further diagnostic tests to explore the presence and extent of DE and endometrioma which can only be achieved through advanced imaging in an endometriosis centre. Likewise, the draft updated NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which is laid down in legislation and is currently released to stakeholders for feedback, confirms that care providers must all refer confirmed or suspected severe endometriosis direct to a specialist endometriosis centre. We suggest that the comment if 'they have pelvic signs of endometriosis' be removed since this is appropriate to section 1.5.5 and not 1.5.4. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it due being against national standards.	
Endometriosis Guidance and Information Resource UK	Table	14	Endometriosis: Diagnosis and Management (NG73), Page 10, lines 26-28. It is advised to refer women and people to a gynaecology service for a gynaecology opinion 'if initial empirical treatment is not effective, is not tolerated or is contraindicated'. We assume that 'initial empirical treatment' is referring to 1.4. but with advances in non-invasive diagnostic approaches,	Thank you for your comment. The committee were clear that women or people with endometriosis should receive pharmacological treatment (such as painkillers or hormonal treatments) to alleviate symptoms after clinical examination and while awaiting or undergoing scans. A new recommendation has been added

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			especially imaging, the ESHRE guideline 2022 now recommends combined clinical examination and imaging (TUS or MRI) as the first approach to identify endometriomas and deep disease early, before empirical medical treatment or referral to explore peritoneal disease (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis), https://www.eshre.eu/Guideline/Endometriosis. We suggest that 'initial' is removed from the comment and that additions are included 'if there are no pelvic signs of endometriosis' and 'if scans are negative'. The rational for change says that ultrasound has been removed on the basis that women would usually have had an ultrasound, but we are not sure what that rationale is based on. We do not feel that assumption can be made but that in any event it is not so much about whether they have had a scan that is relevant, but that any scan was negative. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it.	to the guideline to state that initial pharmacological treatment, ultrasound and referral can all take place in parallel. This means that women or people with suspected endometriosis based on symptoms and clinical examination would not be left untreated and with pain or other symptoms while awaiting an ultrasound scan or secondary care appointment. Ultrasound has been removed from this recommendation as ultrasound is now recommended earlier in the pathway, so it would already have been conducted (as you and ESHRE suggest – imaging should be done to try and obtain a clear diagnosis as an early step in the pathway).
Endometriosis Guidance and Information Resource UK	Table	15	Endometriosis: Diagnosis and Management (NG73), Page 11, lines 12-14. It is said to refer women or people to a specialist endometriosis centre if they have suspected deep endometriosis involving the bowel, bladder or ureter. It is not clear why referrals to endometriosis centres are limited to disease affecting	Thank you for your comment. This recommendation has been amended to clarify that deep endometriosis may affect organs including (but not limited to) the bowel, bladder and ureter, and that people with suspected or confirmed deep endometriosis should be

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			just these areas. Bowel endometriosis only affects up to 12% of those with endometriosis (International journal of women's health, 2013/ AJG Journal, 2022, Chang et al) while urinary tract disease (bladder/ureter) is usually reported as affecting only around 1% of cases. On the contrary, rectovaginal disease is by far the most common and complex presentation of severe endometriosis, involving the rectum/sigmoid being stuck to the cervix/vagina (obliterated POD) with the US ligaments usually involved, affecting up to 37% (International journal of women's health, 2013/ AJG Journal, 2022, Chang et al), and being what the BSGE accredited centres were set up for and what their data collection is based on. Quote: 'Table below shows the annual number of cases of surgery for severe rectovaginal endometriosis undertaken in each centre. This is defined as surgery that required dissection of the pararectal space.' https://www.bsge.org.uk/data-for-bsge-accredited-endometriosis-centres/. In England the treatment of severe endometriosis is prescribed in legislation (Health and Social Care Act, 2012, as amended by the Health and Care Act, 2022). The specification defines severe endometriosis for treatment in centres as all DIE and rectovaginal cases. The specification is currently being updated with the draft released to stakeholders for feedback prior to general consultation. The draft confirms that the scope	referred to specialist endometriosis services. The guideline recommendations on referral to specialist services are in-line with those in the NHS service specification. NICE guidelines and the NHS England service specification cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive. The details of pelvic signs of endometriosis are already defined in the section of the guideline on signs and symptoms so have not been repeated here.

Endometriosis: diagnosis and management – diagnosing endometriosis

Consultation on draft guideline - Stakeholder comments table
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			of severe endometriosis in the new specification remains the same. We have advised NICE of this anomaly several times; it appears that an incorrect section of the 2013 ESHRE guideline was drawn on in 2017 (1.3.7), which advised on pre-lap imaging to assess deep disease rather than 2.4.5, which defined deep endometriosis. We are shocked that this remains, as not only is it discriminatory against those in the devolved boards who can't draw on the NHS England specification, it is against legislation. Current specification: https://www.england.nhs.uk/wp-ontent/uploads/2018/08/Complex-gynaecology-severe-endometriosis.pdf We would request that an additional entry is made 'pelvic signs of endometriosis found on abdominal and/or pelvic examination such as abdominal masses reduced organ mobility and enlargement, tender nodularity in the posterior vaginal fornix and visible vaginal endometriotic lesions'. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it due to being against national standards laid down in legislation.	
Endometriosis Guidance and	Table	16	Endometriosis: Diagnosis and Management (NG73), Page 11, lines 17-27. The draft updated NHS England	Thank you for your comment. The wording 'depending on local provision' has been

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Information Resource UK			service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which is laid down in legislation, is currently published to stakeholders for feedback prior to wider consultation. It confirms that adolescents with confirmed or suspected severe disease are now included in this specification as a mandatory requirement and must be referred to a specialist endometriosis centre, so this is not dependent on local provision. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose part of it.	removed as you suggest, as access to a paediatric and adolescent gynaecology service or a specialist endometriosis service should be available to all young women or people aged 17 or under with suspected or confirmed endometriosis.
Endometriosis Guidance and Information Resource UK	Table	19	Endometriosis: Diagnosis and Management (NG73), Page 12, lines 13-14. The previous section on not using MRI as a primary investigation to diagnose endometriosis in women with symptoms or signs of endometriosis has been removed on the basis that all women would require an ultrasound first. It is recommended at 1.5.2 that if a transvaginal scan is not appropriate a transabdominal ultrasound should be considered. We do not consider this sufficient. Many such people will be adolescents and the ESHRE guideline 2022 recommends that where TUS is inappropriate, MRI, transabdominal, transperineal and transrectal scan may be considered (V.I.e). The time between onset of symptoms and diagnosing	Thank you for your comment. It is recognised that a transabdominal ultrasound scan is less likely to detect endometriosis compared to a transvaginal scan, but would still be likely to identify endometriomas and alternative pathology such as fibroids, and so would be a useful alternative as an initial diagnostic test. A GP cannot order an MRI scan and would need to refer the person which would increase the delay to diagnosis. The recommendations have not therefore been amended and all women or people will receive an ultrasound before

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			endometriosis is reported to be more than 12 years if onset was in adolescence (Geysenbergh, et al. 2017) so it seems likely that many ultimately receiving a diagnosis probably had it from adolescence. Some authors state that that adolescent endometriosis may be more progressive than in adults (ESHRE, 2022, V.I.c) and it seems clear that diagnosing disease early in adolescents is crucial to addressing diagnostic delays. We believe that denying adolescents appropriate imaging (MRI) based on not yet being sexually active to be discriminatory. The draft updated NHS England service specification 'Complex Gynaecology: Severe endometriosis', (E10/S/a), which is laid down in legislation and is currently released to stakeholders for feedback, now provides for adolescents with severe or suspected severe disease to be accepted into specialist centres, and we believe it is their right to have equal access to appropriate diagnostic imaging according to their individual circumstances as provided for by ESHRE guidance, 2022, V.I.e. Likewise, we believe the same applies to anyone for whom transvaginal ultrasound is not appropriate, and that MRI must remain an option when indicated. ESHRE 2022, (Page 187, Annex 5: Flowcharts, Diagnosis of endometriosis). https://www.eshre.eu/Guideline/Endometriosis.	proceeding, if necessary, to an MRI after referral. There is a separate recommendation relating to women or young people who are 17 years or under with suspected or confirmed endometriosis and which advises that they should all be referred to a paediatric and adolescent gynaecology service or a specialist endometriosis service, so this is already in-line with the NHS service specification.

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			We ask that this section be retained, appropriately adapted, to allow for MRI as a primary investigation to diagnose endometriosis in women with symptoms or signs of endometriosis, where transvaginal ultrasound is inappropriate, for example adolescents, those with a history of sexual abuse, post-menopausal women with severe vaginal atrophy etc. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it due to considering it discriminatory for some subgroups with suspected endometriosis.	
Endometriosis Guidance and Information Resource UK	Table	20	Endometriosis: Diagnosis and Management (NG73), Page 12, lines 15-19. Given the placing of this recommendation we assume it applies to secondary and tertiary care settings following referral, so diagnosis in secondary care for onward referral to tertiary centres and in tertiary centres to map the pelvis prior to excision. These are separate applications and in our members' experience the usual procedure in centres is often an advanced ultrasound to assess rectovaginal disease (which might have already been done as part of the referral) followed by MRI for wider mapping of the pelvis. We would suggest that this might read 'consider pelvic MRI and/or specialist ultrasound to diagnose deep endometriosis and assess its extent prior to excision planning'.	Thank you for your comment. It is not usual NICE style to use 'and/or', as using 'or' does not preclude one, other or both investigations being carried out so this change has not been made. As discussed in the response to your comments on recommendation 1.5.5. the definition of deep endometriosis has been extended in several places in the guideline.

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			It is noted that severe endometriosis in this context is described as 'deep endometriosis' in all its locations and the rationale clearly acknowledges rectovaginal disease (vagina, rectosigmoid, POD, US ligaments) as well as bowel, bladder and ureters. It is therefore unclear what the rationale is at 1.5.5 for still only accepting deep endometriosis involving the bowel, bladder and ureters into specialist centres, when this section provides for the full spectrum of severe disease. Suitably adapted, we do not consider the recommendation would be challenging to implement or have significant cost implications.	
Endometriosis Guidance and Information Resource UK	Table	24	Endometriosis: Diagnosis and Management (NG73), Page 15, lines 1-2. We agree that the recording of laparoscopy by imaging such as photographs and video is crucially important. This is supported by the draft evidence review, 2024, page 33, lines 13-17. However, this relates just to diagnostic laparoscopy when we believe it clearly needs to apply to all surgeries, given the high re-operation rates for endometriosis, to inform ongoing treatment for comparison purposes (to identify missed disease or disease progression) and as evidence for medicolegal purposes. We are unable to accept that recording of laparoscopy only applies to initial diagnosis and ask that a suitable additional recommendation be added at 1.10.3.	Thank you for your comment. The section of the guideline on surgical treatment was not within the scope of this update, but to ensure continuity throughout the guideline, the need to record findings with imaging has been added to recommendation 1.10.3 as you suggest.

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			We do not consider the recommendation would be challenging to implement or have significant cost implications, but we consider its scope to be incomplete being limited to just diagnostic laparoscopy.	
Endometriosis Guidance and Information Resource UK	Table	26	Endometriosis: Diagnosis and Management (NG73), Page 15, lines 18-26. It is recommended that if a full, systematic laparoscopy is performed and is normal, explain to women that it is unlikely that they have endometriosis and to offer alternative symptoms management. In view of the diagnostic laparoscopy no longer being the gold standard and considered 'outdated dogma' (ESHRE, 2022, page 20, 1) https://www.eshre.eu/Guideline/Endometriosis we consider this recommendation to be out of date and potentially harmful. In practice diagnostic laparoscopy has only ever been the gold standard for peritoneal disease. The rationale notes the microscopic endometriosis might be missed but historically the failing of laparoscopy has not just been in relation to microscopic lesions but, more relevant in our view, its inability to detect retroperitoneal disease. Many of our members continue to have negative laparoscopies by general gynaecologists, with or without a special interest in endometriosis, and go on to pay privately for expert imaging to discover that they have undetected deep retroperitoneal/rectovaginal	Thank you for your comment. An earlier recommendation already advises that a diagnostic laparoscopy should be carried out by someone with the necessary skills and training so this recommendation has not been amended. A diagnostic laparoscopy is still recommended by the ESHRE guidelines and the committee did not agree that this was an outdated procedure. In addition, while the committee agree that obtaining an accurate diagnosis is very important, they agreed that in women and people who had exhausted all diagnostic procedures and in whom endometriosis had not been found (and so could not be treated surgically), the treatment of symptoms was very important. The committee noted that on occasions an initial diagnostic laparoscopy may not identify endometriosis but that can then be followed a few years later by a positive laparoscopy. They amended the recommendation to emphasise that all diagnostic laparoscopies should be recorded

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			disease. Until such time as advances are made so that all women can be guaranteed expert imaging that will detect all endometriosis, which is likely a long way off yet, we believe that many negative laparoscopies will continue to be performed on women after inadequate non-specialist imaging, who have undetected deep disease. We do not accept that the only aim of treatment is the management of symptoms and consider this to be outdated, since this encourages disease progression. We consider that the aim of treatment is first and foremost the identification of endometriosis to determine appropriate treatment, with pharmacological treatment to relieve symptoms the secondary aim as supported by the ESHRE guideline. We would ask that this recommendation be removed since we believe it will encourage GPs to continue to tell women that diagnostic laparoscopy is the gold standard and that if it is negative then they can't have endometriosis, which is so often not the case and no longer backed by evidence. We are unable to comment on whether the recommendation would be challenging to implement or have significant cost implications as we oppose it due considering it outdated.	with imaging, as this will facilitate a structured assessment of the pelvis which may reduce the likelihood of endometriosis being missed.
Endometriosis UK	General	N/A	There is currently no mention of mental health in the scope, despite mentioning in 2022 surveillance of endometriosis: diagnosis and management (NICE	Thank you for your comment. You are correct that the need for addressing mental wellbeing was mentioned in the 2022 surveillance decision

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			guideline NG73) that mental wellbeing and support would be further considered during scoping of the update. Living with a non-curative chronic pain disease can have a significantly negative impact on a person's mental health as referenced in the Endometriosis in the UK: time for change APPG on Endometriosis Inquiry Report 2020. The survey demonstrated that 95% of participants stated that endometriosis/the symptoms of endometriosis had impacted their wellbeing negatively or very negatively and this should be acknowledged and addressed. Without being recognised, it can lead to symptoms of depression and anxiety. Endometriosis can cause a detrimental impact on a person's social life, affecting their relationships and work or school life which can cause to feelings of isolation without appropriate support. According to our APPG Inquiry 2020[1], 95% of those living with endometriosis report that the condition has a negative impact on their wellbeing. Therefore, the acknowledgment of impact on all aspects of life including mental health, career and relationships is therefore incredibly important.	but in the context that no evidence was found that would support recommendations in this area. As a result the treatment of mental health issues and wellbeing were not included in the scope of this focused update. However, it is recognised that mental wellbeing may be a gap in the guideline and so this will continue to be an issue for the NICE surveillance team to consider when future updates are planned.
Endometriosis UK	Table	1.3	In the 2022 surveillance of endometriosis: diagnosis and management (NICE guideline NG73) it is stated that extra-pelvic endometriosis is outside of the scope because of lack of evidence, however it is disappointing this is not included. Although less common, extra-pelvic endometriosis does still affect many people, with an estimation from the RCOG and BSGE of extra pelvic	Thank you for your comment. As you note the guideline scope does not cover extra-pelvic endometriosis. However, it is recognised that this may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.

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			endometriosis occurring in up to 12% of those with pelvic disease. Currently, there are no guidelines for managing extra-pelvic endometriosis with the only mention of it being in current guidelines is when endometriosis is suspected or confirmed outside of the pelvis, which then warrants a referral to a specialist endometriosis service. We therefore ask that extra-pelvic endometriosis, including thoracic endometriosis, will be reviewed to be included in the scope going forward despite it being a less common involvement of many people's endometriosis symptoms and experience.	
Endometriosis UK	Table	1.3.2	It is positive that awareness of a family history of endometriosis in a first-degree relative increased the likelihood of endometriosis has been added as a recommendation in the guideline. The acknowledgement of a genetic of family link as a potential risk factor could help speed up diagnosis times. However, more research is required to better understand the cause of endometriosis and other risk factors.	Thank you for your comment. This section of the guideline was out of scope for this update but this recommendation was added based on the committee's knowledge and expertise as they agreed it would increase the suspicion of endometriosis and so may lead to earlier diagnosis in some cases. As no evidence review was carried out to evaluate risk factors, it is not possible for the committee to know if there is a research gap in this area.. However, the need to update this section of the guideline on signs and symptoms (including more details of familial links and other possible risk factors) has been passed to surveillance to consider for future updates.

Endometriosis: diagnosis and management – diagnosing endometriosis

Consultation on draft guideline - Stakeholder comments table
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Endometriosis UK	Table	1.4	Endometriosis UK are concerned that there is still no mention of non-pharmaceutical pain management options available, despite endometriosis being a chronic pain condition. Nice Guideline 193 on Chronic Pain refers to using that guideline "alongside NICE guidelines for other chronic pain conditions including …. endometriosis …". Other disease guidelines referred to in 193 have sections on non-pharmacological pain management. Types of non-pharmacological pain management for endometriosis can include, but are not restricted to, physiotherapy, acupuncture, exercise, psychological therapy, devices (e.g. TENS Machines for endometriosis) – all these headings are included under non-pharmacological pain management in one or more of the other NICE guidelines referred to in NG 193.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate non-pharmaceutical pain management interventions. However, it is recognised that non-pharmaceutical options may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Endometriosis UK	Table	10 1.5	The referral to a gynaecologist needs to be made clearer in the pathway and placed before the new recommendation of a referral to an ultrasound scan. Although ultrasound scan can aid the diagnosis of certain types of endometrioses and potentially diagnose other pathology/conditions, normal pelvic ultrasound scan findings do not rule out a diagnosis of endometriosis. This could lead to delays in the referral pathway. Therefore, A referral needs to be a priority to help improve diagnosis time which according to our recently published Diagnosis Report "Dismissed, ignored and belittled", diagnosis times have increased	Thank you for your comment. The committee agreed that if people present in general practice with symptoms and an abdominal or pelvic examination suggests a possible diagnosis of endometriosis or another gynaecological condition, the primary care healthcare professional would carry out these actions (pharmacological treatment, scan and referral if necessary, as described in the guideline) in parallel to expedite relief of pain and other symptoms and to obtain a diagnosis. In many cases of mild endometriosis, if symptoms resolve, no further treatment is necessary, and

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			to a UK average of 8 years and 10 months in the last three years.	referral may not be necessary, so not all people with endometriosis will require a referral. The aim of the guideline is to make the most effective use of gynaecology services, referring those who need to be referred, but not overwhelming services by automatically referring all women or people with endometriosis. The guideline already states that a normal ultrasound does not exclude endometriosis.
Endometriosis UK	Table	11	1.5.1 It is very positive that GPs should offer transvaginal ultrasound to all women or people with suspected endometriosis, even if pelvic or abdominal examination is normal which will speed up diagnosis times. According to our Diagnosis Report 2023, 74% had attended 5 or more GP appointments with symptoms prior to diagnosis and almost half of all respondents 47% had visited their GP 10 or more times with symptoms prior to diagnosis. The new addition of transvaginal ultrasound will improve diagnosis time, but it may also decrease the number of times that patients are currently visiting GPs, therefore providing a cost-effective solution to the NHS. It is also welcoming to see the additional information that is provided for the recommendation for ultrasound which is now provided in the Guideline.	Thank you for your comment. The committee agreed that if people present in primary care with symptoms and an abdominal or pelvic examination suggests a possible diagnosis of endometriosis or another gynaecological condition, the primary care healthcare professional would carry out these actions (pharmacological treatment, scan and referral if necessary, as described in the guideline) in parallel to expedite relief of pain and other symptoms and to obtain a diagnosis. In many cases of mild endometriosis, if symptoms resolve, no further treatment is necessary, and referral may not be necessary, so not all people with endometriosis will require a referral. The aim of the guideline is to make the most effective use of gynaecology services, referring

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			However, we do believe that patients should have a referral to gynaecology prior to an ultrasound and, as per your rationale for change. A normal ultrasound scan does not rule out a diagnosis of endometriosis, therefore results of an ultrasound should not determine the need for a referral. Due to the increase of diagnosis times, patients should not be delayed further to a potential referral by an awaiting outcome of a scan. A referral may enable patients to receive pain management options in the meantime, and medical professionals are also able to understand what the patients' priorities, for example pain management or fertility. Delaying this process will only enable potential endometriosis to progress and cause further damage to organs, as well as a significant decrease in their general wellbeing, as we stated above.	those who need to be referred, but not overwhelming services by automatically referring all women or people with endometriosis. The guideline already states that a normal ultrasound does not exclude endometriosis.
Endometriosis UK	Table	16	1.5.6 We are pleased that this recommendation remains. However, we are disappointed that those who are post-menopausal have been excluded from the scope. We hear regularly from menopausal people that continue to have symptoms due to effects of endometriosis, this can be due to the development of adhesions and pain hypersensitivity. These people are not included in this guideline and unable to access support and management for their symptoms. They may have issues with recurrence alongside hormone replacement therapy, or are left with complications from	Thank you for your comment. You are correct that post-menopausal women are out of scope for this guideline. However, it is recognised that post-menopausal endometriosis may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.

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			endometriosis surgery, such as continuing pelvic pain and reoccurrence. We hope that post-menopausal will be considered in the Guideline when a full review of the Guideline has taken place.	
Endometriosis UK	Table	19	It is positive that the former recommendation (1.5.6) has been removed from the Guideline due to the new recommendation for GPs to refer patients to an ultrasound scan first.	Thank you for your comment.
Endometriosis UK	Table	20	1.5.9 Endometriosis UK are pleased that the addition has been added to the former recommendation (1.5.7) for both "pelvic MRI or specialist transvaginal ultrasound to diagnose deep endometriosis and assess its extent". However, we believe it is important to note that the sensitivity of either imaging modality is highly dependant on the expertise of the operator and interpretation of imaging. Therefore, normal MRI and/or USS findings does not rule out a diagnosis of either deep or superficial endometriosis.	Thank you for your comment. The need for ultrasound scans (as well as MRI scans) to be planned and interpreted by someone with specialist expertise has been added to the recommendations as you suggest.
Endometriosis UK	Table	23	1.5.12 We welcome the new wording of this recommendation. By acknowledging that suspected deep endometriosis may be located in a variety of sites, rather than just the mentioning the three specific areas of 'bowel, bladder and ureter', it is clear that deep endometriosis can affect numerous sites, not just the bowel, bladder or uterus.	Thank you for your comment.

Endometriosis: diagnosis and management – diagnosing endometriosis

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Endometriosis UK	Table	General	The language in the Guideline is consistent. For example, for recommendation • **Analgesics**: 1.4.1, • **Hormonal Treatments:** 1.4.5, 1.4.6, • **Diagnosis and referral for women with suspected or confirmed endometriosis:** 1.5.15 the use of the word 'women' and 'woman's' is only used, and in • **Ultrasound**: 1.5.1, 1.5.4, 1.5.5, 1.5.6, • **Diagnostic laparoscopy** 1.5.11, 1.5.12, 1.5.15 the wording of 'women and people' is used. We strongly suggest that the term' women and people' or used throughout the Guideline, or that 'women and those assigned female at birth' which is currently being used by Endometriosis UK and several Government Bodies across the UK, is instead used to ensure the wording is inclusive and accurate it its recommendation. Inclusivity is extremely important, and it is vital that those who do not define as 'women' or 'woman' are not excluded from this guidance. It is also confusing that 'women and people' are only referenced or recently added in some recommendations and not in others. This also needs to be considered for the recommendations which are not being reviewed on this occasion.	Thank you for your comment. The recommendations on analgesics and hormonal treatments were not included in the scope of this update, they were only included in the table of changes for context or because their position in the guideline had been moved. The use of more inclusive language (women and people) is being rolled out across guidelines as they are updated, and is now included in all the recommendations in the sections of the guideline which were the subject of this update. It is recognised that this may lead to some discrepancies within guidelines in the short term.
Endometriosis UK	Table	General	Endometriosis UK is disappointed that this is only a partial review of the NICE Guideline. We would like to	Thank you for your comment. The surveillance review in 2022 only identified that new evidence

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			stress the importance of a full review of the Guideline, and it would be helpful if you could provide a timeline of when this will be. The key information we would need from a guideline scope is a clear and concise overview of what the guideline currently offers, new updates planned in for the upcoming changes and an overview of what areas these topics will include.	was likely to lead to changes in the recommendations for 2 sections of the guideline (diagnosis and treatment when fertility is a priority). However, as you and other stakeholders have identified, there may be gaps in the completeness of the guideline or other areas which need updating and so this has been passed to the NICE surveillance team for consideration. It is not possible to provide dates for future updates as these will be subject to prioritisation by the new NICE-wide prioritisation board which ensures that limited NICE resources are used to provide advice to the NHS which addresses areas of highest priority.
FTWW: Fair Treatment for the Women of Wales	EIA	3.1	We query the exclusion of post-menopausal patients from the guideline, and would like to see an explanation for this in the 'Age' section of the EIA. Given that severe endometriosis and resultant adhesions can impact on anatomy and organ function beyond menstruation, and that a not insignificant number of patients will undergo early hysterectomy and oophorectomy in an attempt to resolve some of their endometriosis symptoms. we are most concerned at the exclusion of this particular patient group and would ask the Committee not only to provide an explanation in the EIA but commit to the inclusion of post-menopausal	Thank you for your comment. You are correct that post-menopausal women are excluded from the scope of the endometriosis guideline. This decision was originally made at the scoping stage because it was suggested that this topic would be covered in the menopause guideline. As this has not been done, it is now recognised that this is a gap in the completeness of the endometriosis guideline so this has been passed to the NICE surveillance team for

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			endometriosis patients in a future iteration of the guideline. In the meantime, we would urge the Committee to make a recommendation for further research into the experience of endometriosis post-menopause, and how this might be optimally managed.	consideration when future updates are planned, and highlighted in the EIA form. The committee can only make research recommendations where they have carried out an evidence review and identified that there is no evidence or insufficient evidence on which to base recommendations. As no review was carried out on the experience and management of post-menopausal endometriosis, research recommendations cannot therefore be made on these topics.
FTWW: Fair Treatment for the Women of Wales	EIA	3.4	We would ask the Committee to consider referencing geographical location and potential inequities in access to specialist endometriosis services, including the additional barriers to care experienced by those in rural areas.	Thank you for your comment. Geographical location and additional barriers to care in rural communities have been added as potential inequities and barriers to care in the EIA.
FTWW: Fair Treatment for the Women of Wales	EIA	3.5	We would ask the Committee to consider using social model language here, i.e. 'disabled people' and 'people with impairments'. In addition, we would suggest that particular attention be paid to communication barriers potentially experienced by disabled patients, including those who are autistic or have additional learning needs. As much of the guidance pertains to shared decision-making (including linking to a patient decision aid on hormonal	Thank you for your comment. The NICE style is to use 'people with…' to describe people with disabilities or impairments so this has not been changed. The need to make reasonable adjustments for people with autism or learning disabilities is a statutory requirement under the Equality Act 2010 and so this is not stated in all individual NICE guidelines. Further detail on

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			treatment for endometriosis), conversations about benefits and risks of a particular course of action, informed choice, and communicating findings from various interventions, ensuring these needs are considered and accommodated is vitally important. It is also worth pointing out that access to potentially far-distant centralised specialist endometriosis clinics can be more problematic for disabled people, for whom accessible transport might not be readily available or affordable.	communication and treating people as individuals is covered in the NICE guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services, and so this information is not repeated in all other NICE guidelines. This guidance is hyperlinked from the endometriosis guideline section on information and support. The need to travel long distances to endometriosis centres and the additional problems this might pose for people with disabilities has been added to the EIA.
FTWW: Fair Treatment for the Women of Wales	EIA	3.6	The Committee should: • Make a recommendation for further research into the experience of endometriosis post-menopause and optimal management of patients affected • Make a recommendation for healthcare providers (Trusts, Health Boards) to investigate ways to ensure equitable access to specialist endometriosis services for all patients Commit to ensuring patient decision aids are available in easy read (and other accessible) formats.	Thank you for your comment. NICE makes research recommendations when an evidence review has been carried out and there is a lack of evidence identified. As no evidence review was carried out on the experience and care of postmenopausal women with endometriosis, and this population is currently outside the scope of this guideline, hence no research recommendation has been added. The section of the guideline on organisation of care already advises that specialist endometriosis services should be available for women and people with endometriosis and this

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				is being implemented through the NHS service specification for severe endometriosis. Providing patient decision aids in accessible formats is a statutory requirement under the Equality Act 2010 and so this is not stated in individual NICE guidelines. Further detail on communication and treating people as individuals is covered in the NICE guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services, and so this information is not repeated in all other NICE guidelines. This guidance is hyperlinked from the endometriosis guideline section on information and support.
FTWW: Fair Treatment for the Women of Wales	Table	03	Healthcare professionals should be mindful that many patients presenting with potential endometriosis pain will have already self-medicated with analgesics for some time. As part of taking the patient's history, and through a process of shared decision-making, they should be prepared to move straight to the next step of the pathway rather than expecting patients to continue with a regimen they have already trialled and (presumably) found wanting.	Thank you for your comment. The committee were aware that many people present having tried ad-hoc analgesics but often these had not been taken regularly, at an effective dose or combined appropriately. They therefore did not amend this recommendation

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FTWW: Fair Treatment for the Women of Wales	Table	05	Where the guideline links to the NICE Guideline on Neuropathic Pain, it would be helpful if this latter guidance made some mention of endometriosis in its list(s) of populations affected, and conditions for which pharmacological treatments might be offered, particularly where the healthcare professional does not immediately suspect endometriosis and refers to the Neuropathic Pain guideline rather than 'Endometriosis: diagnosis and management'.	Thank you for your comment. The NICE guideline on neuropathic pain is a guideline that covers the treatment of neuropathic pain whatever the cause and does not refer to individual conditions (except trigeminal neuralgia) and does not provide a list of potential differential diagnoses for neuropathic pain. No changes have therefore been made to the recommendations.
FTWW: Fair Treatment for the Women of Wales	Table	06	We are concerned that the NICE patient decision aid on hormonal treatment for endometriosis does not make explicit that hormone-based treatment is not curative of endometriosis or entirely halt disease progression. It is important that patients are enabled to make informed choices, so we would suggest some additional detail be provided regarding the difference between symptom management and disease resolution. In addition to articulating risks associated with hormonal treatment (blood clots etc), the decision aid should make clear that, whilst hormone-based contraceptives might ameliorate symptoms for the duration over which they are used, if / when patients cease usage (perhaps to try to conceive) they may experience both symptom recurrence and issues associated with disease progression, including difficulties getting pregnant.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate treatments. However, NICE is working separately on an update of the patient decision aid for endometriosis to take into account recent work on the guideline. This will be published separately and will not be available at the same time as the publication of this update.

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FTWW: Fair Treatment for the Women of Wales	Table	07	As above, the healthcare professional should explain the difference between symptom management and disease resolution, and the implications of possible disease progression during extended periods of hormonal treatment.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate treatments. However, NICE is working separately on an update of the patient decision aid for endometriosis to take into account recent work on the guideline. This will be published separately and will not be available at the same time as the publication of this update.
FTWW: Fair Treatment for the Women of Wales	Table	11	The Guideline should make a recommendation regarding increased investment in training and provision of specialist ultrasound within outpatient, gynaecology, and emergency settings. Whilst this would incur initial financial outlay, it would ultimately improve efficiency by reducing the chance of missed diagnosis, expediting appropriate care, and improving patient experience and outcomes.	Thank you for your comment. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation, but details of training are not included in the recommendations as this is the responsibility of professional bodies.
FTWW: Fair Treatment for the Women of Wales	Table	15	The Guideline states that patients should be referred to a specialist endometriosis service if they have suspected or confirmed endometriosis outside of the pelvic cavity. However, the guideline does not make clear how those with endometriosis outside of the pelvic cavity might be diagnosed or managed, particularly those with suspected or confirmed extra-pelvic disease, such as diaphragmatic or thoracic endometriosis.	Thank you for your comment. Endometriosis outside of the pelvic cavity is not within the scope of this guideline and so no evidence review was carried out to evaluate its diagnosis and management. It is recognised that extra-pelvic endometriosis may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when

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			More information about how extra-pelvic endometriosis might present is needed so that patients are empowered to seek medical assistance in the first instance, and healthcare professionals have trusted information about symptoms, diagnosis, and management to which to refer. We would advise the Committee to either incorporate information or signpost to reliable external sources for those with suspected or confirmed extra-pelvic endometriosis and to make a recommendation for further research on numbers affected and potential treatment modalities.	future updates are planned. As the committee did not look for evidence on the treatment of extra-pelvic endometriosis they were unable to make a research recommendation.
FTWW: Fair Treatment for the Women of Wales	Table	19	Whilst we agree that pelvic MRI should not be used as a primary investigation to diagnose endometriosis, we would suggest that the guideline make some reference to the possibility of findings consistent with having endometriosis from a coincidental pelvic MRI.	Thank you for your comment. If suspected endometriosis were to be discovered incidentally from an MRI the woman or person would be directed to the appropriate services for treatment, just as they would be for any other incidental findings (such as a tumour or other pathology). No changes to the recommendations have therefore been made.
FTWW: Fair Treatment for the Women of Wales	Table	24	A considerable number of patients report attending regular gynaecology settings for diagnostic laparoscopy during which endometriosis is missed (and subsequently identified when accessing a specialist service). To help resolve this ongoing issue, it would be helpful if the guideline were able to link to a diagnostic proforma to assist gynaecologists in making a thorough	Thank you for your comment. NICE guidelines are designed to provide advice on overall care pathways and do not usually include details such as diagnostic proforma, and such detailed checklists would usually be developed by royal colleges or other professional bodies. However, as the poor diagnosis of endometriosis is a

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			and systematic inspection of the pelvis, indicating possible sites for the disease and providing visual examples of its multifarious appearances. We would also wish the Committee to note also that not all regular gynaecology settings are adequately equipped to offer high quality imaging, and that there can be resultant challenges in sharing useful images and interpretations with both patients and subsequent healthcare providers. It may be that the Committee makes a recommendation pertaining to investment in imaging equipment, given that it is both an expectation and integral part of the diagnostic pathway.	known problem this suggestion has been passed to the NICE team responsible for implementation for consideration when planning support activities. Likewise, the availability of imaging equipment to enable the guideline recommendations to be put into practice is an implementation issue and not one that would be included in NICE recommendations. This suggestion has also been passed to the NICE team responsible for implementation for consideration when planning support activities.
FTWW: Fair Treatment for the Women of Wales	Table	25	We would suggest that 'consider taking a biopsy of suspected endometriosis' is strengthened, both to reduce chances of a missed diagnosis but also to assist in excluding malignancy.	Thank you for your comment. The committee discussed this but agreed that in some cases it may not be necessary to take a biopsy (for example if endometriosis was excised at the time of the diagnostic laparoscopy), or if it was considered too risky, or was not possible to insert another laparoscopic port. This recommendation has therefore not been changed.
FTWW: Fair Treatment for the Women of Wales	Table	26	We are concerned that this recommendation does not reflect many patients' experiences of ineffective diagnostic laparoscopy in non-specialist settings and would advise that there be a recommendation for	Thank you for your comment. An earlier recommendation already advises that a diagnostic laparoscopy should be carried out by someone with the necessary skills and training so this recommendation has not been amended.

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			investment in advanced laparoscopic skills training in regular gynaecology settings.	
Medtronic Limited	EIA	N/A	Medtronic acknowledge the comprehensive coverage of areas within the "equality impact assessment". It provides a robust assessment of the potential impacts and demonstrates a commitment to addressing equity in treatment access for patients.	Thank you for your comment.
Medtronic Limited	Table	11	The proposed changes specify that "GPs should offer a transvaginal ultrasound to patients with suspected with suspected endometriosis, even if pelvic or abdominal examination is normal." We believe that there is ambiguity regarding whether GPs should directly provide ultrasound services or solely refer patients to a specialist. We kindly request for clarification on this recommendation and precise language to avoid misinterpretation. If the intention is for GPs to solely to refer patients for an ultrasound to aid diagnosis, we would like to propose the following amendment: ***"GPs should refer patients for a transvaginal ultrasound to patients with suspected with suspected endometriosis, even if pelvic or abdominal examination is normal."***	Thank you for your comment. The committee decided that using the terminology 'refer' in this recommendation would add confusion as this terminology is usually associated with obtaining an expert opinion from a specialist in a secondary care provider. The intention of this recommendation was to advise that an ultrasounds should be requested directly by a healthcare professional in general practice and although usually carried out by a sonographer at a different physical location this would not usually be viewed as 'making a referral'. This recommendation has therefore been changed to clarify that the ultrasound should be 'organised by the person's general practice'.
Medtronic Limited	Table	General	Medtronic would like to thank NICE for the opportunity to comment on this clinical guideline and supporting evidence review documents.	Thank you for your comment.

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			Medtronic welcomes the proposed draft recommendations and anticipate that their implementation will align clinical standards from patient diagnosis and treatment and improve the patient pathway.	
NHS England	Table	1.3.2	The knowledge of a family history of endometriosis in a patient may increase the likelihood of diagnostic curiosity and therefore have an impact on referral for further investigations including an impact on diagnostics such as US. As patients become more aware of this risk factor there may be a slight increase in patients presenting to their GP/primary care provider.	Thank you for your comment. The committee were aware that failure to diagnose endometriosis is a concern, as the average length of time to obtain a diagnosis is 8 years. They agreed that any factors which could increase suspicion of endometriosis, such as family history, would therefore be useful and while this may increase the number of people undergoing further diagnostic tests this would be a benefit if it led to earlier diagnosis. The committee did not think that including family history as a risk factor would increase the number of people presenting to their GP as only symptomatic people are likely to present, not those who are asymptomatic but have a family history. The impact statement relating to this new recommendation has been revised to clarify this.
NHS England	Table	11	Offering all women transvaginal US with a normal examination but suspicious history is unlikely to have an impact on workload as the patient is still	Thank you for your comment.

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			symptomatic and would require further investigation in any case.	
NHS England	Table and EIA	n/a	Just a general comment on the absence of any guidance on positive lifestyle measures. There are many published articles on qualitative studies where patient symptoms improved with measures such as advice on diet, weight management, exercise, alcohol, smoking etc. Whilst there has not been any quantitative studies there will be an impact of chronic pelvic pain on mood and mood can be improved by supporting the patient to improve their lifestyle. This helps empower patients and gives them a sense that they are doing something positive for themselves, and it certainly won't have a negative impact on their health. Raising mood also reduces the reliance on more potent analgesics. However, as with any positive lifestyle intervention these choices will have a disproportionate disadvantage for patients in lower income groups, those with other chronic disease, severe mental ill health and LD&A etc.	Thank you for your comment. The treatment of endometriosis was not within the scope of this focused update and so no evidence review was carried out to evaluate lifestyle measures. However, it is recognised that use of lifestyle measures may be a gap in the guideline and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Pelvic Pain Support Network	General	General	General comment regarding lack of expertise and access to appropriate equipment in imaging of endometrioma and deep endometriosis.	Thank you for your comment. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline, as well as

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				ensuring the availability of the equipment. This has been added to the impact statement for this recommendation.
Pelvic Pain Support Network	Table	1.5.2	Concern that presence of endometrioma on U/S which is often reported non specifically as "cyst(s)" will continue to be ignored/considered unimportant. It is known that the existence of endometrioma can also indicate presence of deep disease. Lack of sensitivity in U/S detection of deep disease	Thank you for your comment. The committee considered that the differential identification of endometriomas and other pathology such as haemorrhagic cysts was a training issue, and have now included this in the impact section for this recommendation. The evidence review conducted for this update showed that ultrasound was sensitive enough to recommend it as a tool to identify endometriomas and deep endometriosis.
Pelvic Pain Support Network	Table	1.5.3	A transabdominal U/S is even less likely to identify deep disease even if endometrioma is detected. MRI with an experience radiologist should be offered in this case.	Thank you for your comment. It is recognised that a transabdominal ultrasound scan is less likely to detect deep disease compared to a transvaginal scan, but it would still be likely to identify endometriomas and alternative pathology such as fibroids, and so is useful as an initial diagnostic test. A GP cannot order an MRI scan and would need to refer the person which may increase the delay to diagnosis and so this has not been recommended as an alternative at this stage in the pathway.

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Pelvic Pain Support Network	Table	1.5.7	Concern around lack of U/S experience along with poor access to latest technology to make this a reality. U/S involves a vaginal probe which can be unpleasant/impractical/possibility of inadvertently introducing infection. MRI is less invasive, less biased, can be reviewed. Patient preference is very important here. MRI protocol needs attention in the UK: appropriate software, bowel prep, glucagon to improve detection of widespread and deep disease.	Thank you for your comment. Your comment relates to the recommendation on use of CA125 but discusses the use of ultrasound. The committee noted concerns about the sonographic skills needed to diagnose endometriosis using non-specialist ultrasound and were aware that additional training may be necessary but chose to make recommendations on the diagnostic method shown to have good diagnostic accuracy, rather than base recommendations on what current staff are able to achieve, and to recognise that training will be required to implement the guideline. This has now been included in the impact section for this recommendation, The committee were aware that diagnostic accuracy was greater with transvaginal ultrasound than transabdominal ultrasound and therefore, despite the limitations you state, recommended transvaginal as the preferred method of ultrasound. MRI cannot be accessed directly by general practice and would therefore need a referral for the person which may increase the delay to diagnosis. The committee were aware that MRI scans need to be conducted and interpreted by someone with the necessary expertise and included this in a separate recommendation.

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Royal College of General Practitioners	Table	1.3.2	If we are going to relate Endometriosis to a family history, it would be good to understand the relative risks i.e. around 6% additional information advised	Thank you for your comment. This section of the guideline was out of scope for this update but this recommendation was added based on the committee's knowledge and expertise as they agreed it would increase the suspicion of endometriosis and so may lead to earlier diagnosis in some cases. As no evidence was reviewed the committee were unable to add any more detail about the absolute or relative increase in risk. However, the need to update this section of the guideline on signs and symptoms (including more details of familial links) has been passed to surveillance to consider for future updates.
Royal College of General Practitioners	Table	11	Re Ultrasound – We are concerned that this shall lead to an increase in ultrasound waiting lists (some waiting lists are already long for USS) some radiology departments are advising CA125 before gynae USS as a way of limiting scans. It would be beneficial to include a statement regarding this, in this section as it causes unnecessary anxiety and waits – links to 17 and 18	Thank you for your comment. Serum CA125 should not be used to diagnose endometriosis (this is stated in recommendation 1.5.8) and therefore there is no benefit in carrying out this as a way of limiting scans. In order to simplify this message, a subsequent recommendation which contained information about coincidentally reported CA125 levels has been removed.
Royal College of General Practitioners	Table	17 18	See above re links to CA125 and USS	Thank you for your comment. Serum CA125 should not be used to diagnose endometriosis (this is stated in recommendation 1.5.8) and therefore there is no benefit in carrying out this

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				as a way of limiting scans. In order to simplify this message, a subsequent recommendation which contained information about coincidentally reported CA125 levels has been removed.
Royal College of Obstetricians and Gynaecologists (RCOG)	Table		1.3.2 How much is the increase in OR of a particular patient having a subsequent diagnosis of endometriosis with a positive family history. It might be useful to quantify this increase so that the decision between the patient and their doctor to investigate further can be better informed.	Thank you for your comment. This section of the guideline was out of scope for this update but this recommendation was added based on the committee's knowledge and expertise as they agreed it would increase the suspicion of endometriosis and so may lead to earlier diagnosis in some cases. As no evidence was reviewed the committee were unable to add any more detail about the absolute or relative increase in risk. However, the need to update this section of the guideline on signs and symptoms (including more details of familial links) has been passed to surveillance to consider for future updates.
Royal College of Obstetricians and Gynaecologists (RCOG)	Table	08	Page 11 I am not an endometriosis specialist but my only concern comes from the wording "this would allow identification of deep endometriosis" – to me this suggests that if there was deep endometriosis this would definitely be seen on ultrasound. Many women in my service will have an initial ultrasound by a	Thank you for your comment. The committee agreed that the aim of this scan, as specified in the recommendation and reiterated in the rationale was to identify deep endometriosis, endometriomas, or other pathology. The fact that this is not always possible is covered in a subsequent recommendation that says 'Do not

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			sonographer who may not be a specialist in gynaecology, they will see endometriomas but I worry that nodules of deep endometriosis could be missed and my reading of the current wording is that if there is deep endo it will definitely be seen. If this is the case then no edits needed but if it is possible in the initial ultrasound that deep endometriosis could be missed perhaps change the wording to "may aid in the identification…" or "is likely to aid…"	exclude the possibility of endometriosis if the …ultrasound [is] normal…' This recommendation has not therefore been amended.
Royal College of Obstetricians and Gynaecologists (RCOG)	Table	11	1.5.1 What ultrasound findings would suggest that a GI referral is the appropriate direction? If it is a 'normal scan' - that could equally suggest referral to gynaecology by the GP for non-ovarian non-DIE endometriosis. One of the reliable findings in ultrasound for evidence of DIE is hydronephrosis or hydro-ureter. This would indicate something serious such as DIE obstructing renal outflow risking long term renal function, or something malignant such as cervical cancer. This is a straightforward and low risk addition to the TVUSS described, and in the women where it is found should lead to a recommendation for expedited treatment, checking of urea/cretanine plus additional steps such as ureteric stunting to protect the upstream kidney.	Thank you for your comment. The committee discussed this and agreed that there could be a number of findings on the ultrasound scan (for example fibroids, tumours, diverticulitis) that would warrant referral to a number of different specialists and so removed the example of gastroenterology from this recommendation. The committee agreed that the identification of hydronephrosis or hydro-ureter would require expedited care, although this could also apply to other conditions such as tumours. The committee therefore agreed to leave this recommendation open and not include this as a specific example.
Royal College of Obstetricians and	Table	13	1.5.3	Thank you for your comment. This recommendation advises that a normal scan

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Gynaecologists (RCOG)			If a patient with sub fertility or previous endometrioma had a TVUSS - it seems reasonable to say that endometriOMA can be excluded by the scan.	cannot exclude endometriosis completely, even if it can exclude the presence of an endometrioma, so it has not been changed.
Royal College of Obstetricians and Gynaecologists (RCOG)	Table	21	1.5.10 If an MRI is performed and interpreted in in a hospital which does not have a specialist in gynaecology MRI, does the term ensure here means the Radiologist should refer the images for a second opinion to another centre. I am unclear from the way the statement is written WHO should ensure this happens - the person requesting the MRI, or the radiologist reporting it?	Thank you for your comment. The committee agreed that in some cases images performed in local centres may be reviewed in specialist services if necessary, and that the responsibility for doing this would be with the healthcare professional requesting the scan. As this is not precluded by the current wording of the recommendation, no changes were made.
Royal College of Obstetricians and Gynaecologists (RCOG)	Table	24	1.5.13 There is a spectrum of endometriosis found in the pelvis from Superficial peritoneal endometriosis to deep infiltrating. Some of these require specialist skills/training to excise or treat surgically. I am sure that ANY gynaecologist who is able to competently perform a diagnostic laparoscopy, should be able to record in their operation note a FULL SYSTEMATIC LAPAROSCOPY, as indicated in 1.5.15 (Row 26). The capture of photographs and the ability to store these in the patients medical records for later retrieval I think is particularly useful for optimising patient care if the general gynaecologist where to subsequently refer to a gynaecologist with endometriosis expertise. I wonder if this aspect of retaining the information generated by performing the laparoscopy is one of the	Thank you for your comment and support of the recommendations relating to conduct of a diagnostic laparoscopy and the capture of images. However, NICE guidelines are designed to provide advice on overall care pathways and do not usually include details such as diagnostic proforma, and such detailed checklists would usually be developed by royal colleges of other professional bodies. However, as the poor diagnosis of endometriosis is a known problem this suggestion has been passed to the NICE team responsible for implementation for consideration when planning support activities.

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			key points for improving the time between symptoms and definitive surgery for the patients suitable for this. This might support centres to upgrade their laparoscopy stacks where this function does not current exist. Moreover, without the description of what a full systematic laparoscopy is, there is the potential for information to be missed and a downstream misalignment of theatre planning/resources to the operation required for the patient. The ESPIRIT2 trial incorporates a set of 'standard laparoscopic images' which include pelvic organs, common sites of pelvic peritoneal endometriosis, appendix, and upper abdomen/diagphragms. Something along those lines would be very helpful in excluding endometriosis as far as laparoscopy is able to when the findings are normal - and to reduced the need for patients to have a second laparoscopy to complete the full survey, or for newly recognised findings leading to abandonment of surgery due to limitations of what had given consent for.	
Social SciencEs Endometriosis Network - SEEN	EIA	Evidence Review	We have queries regarding the Evidence Review on which the recommendations are based. The review is based on the notion that diagnostic delays are mainly linked to diagnostic modalities. While accurate diagnostic tests are essential to addressing delays, the review would benefit from evaluating who is considered to have 'suspected endometriosis' with attention to overlooked populations/subgroups. Further, the	Thank you for your comment. The evidence review included all symptomatic and asymptomatic women and people with suspected endometriosis, however defined by the study, and it is not clear from your comment which populations you believe have been over-looked.

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			limitations of the Evidence Review should be better acknowledged, specifically that available data on diagnostic modalities are based on populations samples that do not include many subgroups of endometriosis patients. Thus, evidence generated with *some* populations is currently used to inform guidance for diagnosis and management of *all* populations with endometriosis.	
Social SciencEs Endometriosis Network - SEEN	EIA	n/a	We recommend changing the following statement within the introduction of what the guidance covers from "…what action to take when women with signs and symptoms first present in healthcare settings" to, "…what action to take when patients with signs and symptoms present in health care settings.' Doing so includes adolescents and gender diverse individuals with endometriosis and removing the word 'first' is preferable as patients may present multiple times in a healthcare setting before being evaluated for endometriosis.	Thank you for your comment. This has been changed to 'women and people' as this is NICE style for gender inclusive language, rather than 'patients'. The word 'first' has also been removed as you suggest.
Social SciencEs Endometriosis Network - SEEN	EIA	n/a	The Equality Impact Assessment for the guidance does not recognise the evidence that patients from ethnically minoritised groups are more likely to have their pain dismissed, see: Black women's menstrual and reproductive health: a critical call for action in the UK | The BMJ. The assessment currently only states that such groups may be more likely to be misdiagnosed or face culture-based barriers to talking about menstruation (which 'blames' culture, locates the	Thank you for your comment. The evidence that those from Black, Asian and minority ethnic groups face more barriers talking about menstrual health than other cultures was taken from the 2018 APPG report on endometriosis and therefore this has not been extended to a taboo that affects all communities. However, the APPG did also find that these same groups 'did not feel believed' by healthcare professionals

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			problem as a community one, and overlooks that taboos about talking about menstruation exists across all communities, not only those from ethnically minoritised communities). Please consider how the guidance might provide an opportunity to note health practitioners should consider any unconscious bias when patients present with pain.	when reporting their symptoms as you have suggested, so this has been added to the EIA. In addition, a new recommendation based on the committee's expertise and experience has been added to raise awareness of the need to take diversity issues into consideration when assessing pain symptoms.
Social SciencEs Endometriosis Network - SEEN	Table	1.3.1	We recognise that this recommendation is not part of the revision. However, we are concerned about the absence of non-pelvic symptoms, contributing to outdated understandings/definitions that endometriosis is solely a pelvic condition.	Thank you for your comment. The signs and symptoms of endometriosis were not within the scope of this focused update and so no evidence review was carried out. However, as you and other stakeholders have identified, there may be other sections of the guideline which need updating, including the list of signs and symptoms, and so this has been passed to the NICE surveillance team for consideration when future updates are planned.
Social SciencEs Endometriosis Network - SEEN	Table	1.3.2 [ID # not provided but is in Proposed Revision column]	We are concerned this recommendation does not recognise that first-degree relatives may have had endometriosis but were not diagnosed. We recommend adding a note that endometriosis should still be considered even if patients do not have a first-degree relative with diagnosed endometriosis.	Thank you for your comment. This recommendation suggests a risk factor which may increase the likelihood of suspicion of endometriosis. It does not advise or imply that that endometriosis can be ruled out if there is no family history, so the change you suggest has not been made. It is not possible to make recommendations about first-degree relatives who may have had endometriosis but were not

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				diagnosed as their medical history would be unclear.
Social SciencEs Endometriosis Network - SEEN	Table	11	We welcome this strengthened wording from 'consider' to 'should offer' as this ideally will lead to less dismissal of patients with suspected endometriosis.	Thank you for your comment.
Society and College of Radiographers	Table	11	It would be of benefit to ensure 'suspected endometriosis or ? endometriosis' is included in the clinical indication, when requesting the ultrasound examination, to allow departments to vet the request and allocate to an appropriate ultrasound practitioner. It would be helpful to also request that the signs and symptoms of endometriosis including family history are included in the ultrasound referral. It would also be useful to recommend that GPs inform patients in advance that a transvaginal scan will be offered, so that women and people have time to consider this, ask questions and if necessary, make contact with the clinical department in advance of the appointment. This is essential for consent and trauma informed care.	Thank you for your comment. The committee agreed that requests for ultrasound would usually give some indication of the reason for the scan, but that giving a suggested diagnosis and focusing the instructions to the sonographer on endometriosis may lead to other pathology being missed. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation. The committee discussed that the consent for the scan would include the preference for a transvaginal scan, or the option for a transabdominal scan if transvaginal was not acceptable and so this level of detail has not been added to the recommendations. However, the wording has been amended to clarify that

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				the person can decline the scan and it is not just the healthcare professional who decides if it is appropriate.
Society and College of Radiographers	Table	11	**However, the committee agreed that a non-specialist ultrasound was still a useful tool that would help identify deep endometriosis (or endometrioma or other pathology)** Non-specialist sonographers might not be trained to identify deep infiltrating endometriosis and might only identify ovarian endometriomas or abnormal positioning of the uterus and ovaries which might be suggestive of endometriosis. It would be helpful to include something such as: All Sonographers should be given training in identifying endometriosis as patient may first present for scan via GP and a good knowledge of endometriosis identification on scan could help speed up patient management. The Society of Radiographers Ultrasound Advisory Group suggested that the sonography workforce as a whole need to be upskilled to ensure that all sonographers are able to assess for DIE, so that it becomes part of the standard gynaecological ultrasound examination.	Thank you for your comment. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation. The committee discussed whether it would be appropriate to include the level of detail you have suggested in the recommendation but agreed this may be too limiting, as the purpose of the initial ultrasound scan was to determine if there was any abnormal pathology in the pelvic and abdominal area which may or may not include endometriosis, and that focusing the instructions to the sonographer on endometriosis may lead to other pathology being missed.

Endometriosis: diagnosis and management – diagnosing endometriosis

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			If not, it would at least be helpful to include something such as: Recommended standards for a specialist scan for endometriosis by a specialist doctor or sonographer should include: 1. Routine assessment of uterus, ovaries and adnexae 2. Check pelvic organ location (uterus and ovaries) for non-specific signs of adhesions 3. Assess pelvic organ mobility using the sliding sign 4. Assess the uterosacral ligaments and rectum (posterior fornix) for DIE 5. Report on a normal scan could include a statement such as *"A negative/normal ultrasound scan does not definitively exclude endometriosis"*	
Society and College of Radiographers	Table	11	Impact column Upskilling of all gynaecological sonographers to assess for deep endo should be planned for, and that the minimum of this assessment should be stipulated in the guidance to aid local SOP development.	Thank you for your comment. The committee agreed that there was a need to upskill sonographers who scan women or people with suspected endometriosis, and that the training of sonographers may be necessary to allow full implementation of the guideline. This has been added to the impact statement for this recommendation. The committee discussed whether it would be appropriate to include the minimum for this assessment as you have

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				suggested in the recommendation but agreed this may be too limiting, as the purpose of the initial ultrasound scan was to determine if there was any abnormal pathology in the pelvic and abdominal area which may or may not include endometriosis, and that focusing the instructions to the sonographer on endometriosis may lead to other pathology being missed.
Society and College of Radiographers	Table	12	**If a transvaginal scan is not appropriate, consider a transabdominal ultrasound scan of the pelvis. [2017]** There are substantial limitations when using transabdominal ultrasound in the assessment of the pelvis, particularly for endometriosis. Suggested change would be 'If a transvaginal scan is not appropriate, consider a transabdominal ultrasound scan of the pelvis but appreciate that a transabdominal ultrasound has substantial limitations in the diagnosis of endometriosis, other than to identify large ovarian endometriomas.'	Thank you for your comment. This recommendation has been clarified to state that the reasons for not carrying out a transvaginal ultrasound may be because the woman or person with endometriosis does not wish to have this internal scan or if there are other reasons which mean it is not suitable for the person. The committee did not add the limitations of transabdominal scanning to the recommendation as they agreed this might put undue pressure on women or people to undergo an unwanted invasive investigation.

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*