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Stakeholder	Page no.	Line no.	Comments	Developer's response
British Society for Gynaecological Endoscopy	3	14-19	The provision of advanced laparoscopic surgery for severe endometriosis in UK Trust is frustrated by the poor tariff payments for the complex surgery. The inadequate reimbursement prevents some Trusts from taking on the surgery and limits geographical provision of services. This needs to be addressed in the economic aspects of the guideline.	Thank you for your comment. Economic aspects are considered in all areas of the scope in accordance with NICE processes.
British Society for Gynaecological Endoscopy	3	12	Adenomyosis is a significant part of endometriosis management and in the UK appears underdiagnosed and poorly managed. Consequently we advise that the guidance should include Adenomyosis even if this occurs in isolation	Thank you for your comment. We have not excluded adenomyosis co-occuring with endometriosis. However, we have excluded the management of adenomyosis in isolation because this falls outside the remit of an endometriosis guideline.
British Society for Gynaecological Endoscopy	4	31/32	To determine the costs effectiveness the true cost of surgery will need to be taken into account and at present the tariff system is understating costs. In terms of benefit; improvement in quality of life needs to be included. Data on the improvements in quality of life is present in the BSGE unpublished dataset referred to above.	Thank you. Your comment has been noted to inform the health economic analysis on surgery for endometriosis.
British Society for Gynaecological Endoscopy	4	6	Complex ovarian cysts which are in fact endometriomas are often referred to Gynaecology Oncology rather than endometriosis centres. The use of the biomarker HE4 can usefully differentiate endometriomas from ovarian malignancy and should be reviewed in the guidance.	Thank you. The use of biomarkers will be considered in the review on diagnostic tests, and we have noted your comment.

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British Society for Gynaecological Endoscopy	4	7	Surgical diagnosis is often made by laparoscopy, which is considered the gold standard diagnostic test. However poor quality laparoscopy can lead to false negative findings. Diagnostic laparoscopy should only be considered adequate if the small bowel and any free fluid is cleared from the pelvis before a careful structured pelvic survey is undertaken. When reviewing the diagnostic sensitivity and specificity of laparoscopy this needs to be taken into account.	Thank you. The accuracy of surgical diagnosis will be considered in the review of diagnostic tests, and is also relevant to the planned review on staging systems. We will draw your comment to the atttention of the committee.
British Society for Gynaecological Endoscopy	4	9	Histological confirmation of endometriosis is required with less experienced laparoscopists, but endometriosis experts in specialist centres should make the diagnosis on visual inspection alone. Therefore any recommendation on the use of histology should reflect surgical experience of endometriosis.	Thank you for your comment. The value of histological confirmation of diagnosis will be addressed in this review question. However, NICE guidelines make recommendations on treatment and processes of care rather than specifying roles, training and experience of healthcare professionals. We are aiming to include a Histopathologist as an expert witness.
British Society for Gynaecological Endoscopy	4	22	The BSGE has unpublished data on the worlds largest study of surgical excision of endometriosis in women with severe rectovaginal endometriosis performed in multiple centres. These data will hopefully be published soon but are available for	Thank you for drawing our attention to this and for making BSGE data available for review by NICE. We have noted this and will bring it to the attention of the committee.

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			review by NICE.	
British Society for Gynaecological Endoscopy	8	22/23	The comparison between ablative or excisional surgery is limited by the difficulty in making an objective comparison. Lack of histological confirmation and risk of damage to underlying structures need to considered when considering the effectiveness of ablative therapy. Selection bias may also influence comparison, as less skilled laparoscopic surgeons are likely to use ablation. Specialist centres favour laparoscopic excisional surgery but this requires significant expertise.	Thank you for your helpful comment. We have noted all your points and will consider these when agreeing the details of the plan for this topic review with the committee.
British Society for Gynaecological Endoscopy	8	25/26	BSGE Endometriosis centre multidisciplinary teams include a colorectal surgeon as the most active and relevant surgical member after the Gynaecologist and this should be included in the list of multidisciplinary members.	Thank you for your comment. We agree that multidisciplinary input is important during guideline development and will include a colorectal surgeonas an expert witness to the Committee.
British Society for Gynaecological Endoscopy	8	17	The effectiveness of ultrasound, MRI or any other imaging techniques vary with the ability of the radiologist and /or radiographer and cannot be assume to be universal and therefore the use of the investigations can vary between centres based on local expertise. This qualitative assessment	Thank you for your comment. A radiologist with special interest in pelvic imaging will contribute to guideline development. However, NICE guidelines make recommendations on treatment and processes of care rather than specifying roles, training and experience of healthcare professionals.

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Stakeholder	Page no.	Line no.	Comments	Developer's response
			needs to be included in the review of data.	
British Society for Gynaecological Endoscopy	9	19	In BSGE endometriosis Specialist centres hysterectomy is rarely needed in skilled surgical treatment of severe endometriosis. Removal of the endometriosis wherever it is present is the surgical aim. In addition patients often wish to preserve their fertility. The only reason to remove the uterus would be to treat Adenomyosis. Whereas inexperienced gynaecologists are morel likely to advise an open hysterectomy and removal of both ovaries as definitive treatment for severe endometriosis. Ironically the endometriosis deep in the rectovaginal septum is often left behind. So the net result is that the normal tissue is removed and the disease left. Nationally the figures will show a higher rate of hysterectomy as treatment for endometriosis as a reflection of lack of surgical expertise not necessarily as a reflection of the appropriate treatment.	Thank you for your comment. The guideline scope includes a review of effectiveness of different surgical treatments for endometriosis, including hysterectomy, and your comment has been noted. However, NICE guidelines make recommendations on treatment and processes of care rather than specifying roles, training and experience of healthcare professionals.
Edinburgh University	General	General	Suggest the following topics for separate NICE 'clinical guidance' papers: Care of women with endometriosis during	Thank you for your comment. We will ensure that this is passed on to the NICE Topic selection panel as a suggestion for the development of future guidelines.

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			pregnancy Care of women with endometriosis outside the pelvis Care of women with adenomyosis	
Edinburgh University	2	10	Will the NICE menopause guideline cover the management of post-menopausal endometriosis in detail? If not should this not be included in this guideline? This is complex and would benefit from recommendations.	Thank you for your comment. The NICE Menopause guideline does not specifically cover the management of post-menopausal endometriosis. This condition has a low prevalence and NICE guidance is intended to cover the majority of women.
Edinburgh University	2	17	When (and where) should clinicians refer to an endometriosis specialist?	Thank you for your comment. This will be addressed in the guideline in the review questions on timing of referral and also the effectiveness of specialist services.
Edinburgh University	2	21	Will the guideline cover the validity of current staging systems to manage women with endometriosis?	Thank you for your comment. We agree that this is important and information which will usually be extracted if and when it is reported in primary studies. However, we will not carry out validations of individual systems and therefore will not add validity explicitly to the scope document.
Edinburgh University	3	8	The existing NICE infertility guidelines are not sufficient for the management of women with endometriosis and infertility. I feel that this aspect	Thank you for your comment. We will include fertility as one of our outcomes and cross reference to the Fertility guideline (CG 156).

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			of patient care should be included in the new guideline.	
Edinburgh University	4	14	Change to 'Does early diagnosis and treatment improve outcomes?	Thank you for your comment. This key question is 'timing of interventions' and we intended to review laparoscopy in this context, as an intervention rather than diagnosis. We will try to clarify this when the detailed review questions are developed.
Edinburgh University	4	16	Change to 'What is the extent of the effectiveness of the following treatments?'	Thank you for your comment. 'Extent' implies that we are certain that they are effective already. We believe there is uncertainty in clinical practice and will therefore not amend this.
Edinburgh University	4	23	Include surgical mode of hysterectomy and use of HRT post-hysterectomy	Thank you. Different methods of hysterectomy are not excluded from this topic and can feature as a subgroup analysis; we will draw the committee's attention to your comment. The use of HRT is not included in the scope as NICE guidance on Menopause is in development.
Edinburgh University	4	27	Change 'non-medical' to 'complementary' throughout	Thank you for your comment, however we believe that not all 'non-medical' management can be classed as 'complementary'.
Edinburgh University	4	30	What are the criteria for being seen in a specialist centre?	Thank you for your comment. This will be addressed in the review questions on referral and

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				specialist services.
Edinburgh University	5	1	Include 'What are the short and long term risks of developing comorbidities (incl cancer) in women with endometriosis?'	Thank you for your comment. We will take note of this in developing the review on information needs. It will now be addressed in section 1.5.2 on monitoring.
Edinburgh University	5	10	Define 'pain' i.e. dysmenorrhea, dyspareunia, dyschesia, dysuria, etc..	Thank you for your comment. We will include your point when developing the detailed review questions.
Edinburgh University	5	14	Change to 'Recurrence of endometriosis symptoms (+/- evidence of disease)'	Thank you for your comment. All of the outcomes in this section are left deliberately broad. We will provide detailed descriptions of outcomes for each topic in a comprehensive plan for each review question.
Edinburgh University	7	5	Cause of endometriosis is unknown. 'Theories include…"	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problem which the Guideline will address. It is therefore not a comprehensive summary of all aspects related to endometriosis.
NHS Choices	General	General	We welcome the guidance and have no comments on the content as part of the consultation.	Thank you for your comment.
Pelvic Pain Support Network	General	General	We would favour a radiologist with special interest in pelvic imaging : ultrasound including 3D and	Thank you for your comment. The number of full committee members from health professions is

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			MRI as a full committee member (not just a witness)	limited but a radiologist with special interest in pelvic imaging will be invited for all relevant committee discussions.
Pelvic Pain Support Network	General	General	We would like to see a gastroenterologist and a general surgeon added to the list of expert witnesses.	Thank you for your comment. We agree that multidisciplinary input is important. After discussion at scoping meeting 3, a colorectal surgeon and urologist have been invited as expert witnesses
Pelvic Pain Support Network	2	10	The draft scope currently excludes postmenopausal women. We feel this group should be included as no other guideline would cover this group. There needs to be recognition that this exists. Why should older women in this group be excluded even if it is not common ? what happens to these women ?	Thank you for your comment. NICE guidance on Menopause is in development. However, post-menopausal endometriosis has a low prevalence and NICE guidance is intended to cover the majority of women.
Pelvic Pain Support Network	2	17	Recognition of deeply infiltrating endometriosis and severity of pain is a major issue. See comments about pain above.	Thank you for your comment. We agree that this is an important issue and we hope that implementation of the Guideline will improve recognition of these problems.
Pelvic Pain Support Network	3	8	Investigation of fertility/subfertility problems relating to endometriosis need to be covered in both guidelines and linked. Fertility specialists are not always familiar with endometriosis related problems, so there is a strong argument for	Thank you for your comment. We will include fertility as one of our outcomes and cross reference to the Fertility guideline (CG156).

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			including this in the Fertility guideline.	
Pelvic Pain Support Network	4	9	Histology is very important and particularly in deep disease, however it is rarely carried out/communicated to the patient. We feel the histology should be documented and the information shared with the patient.	Thank you for your comment. This is covered in section 1.5.3 of the scope.
Pelvic Pain Support Network	7	24-25	It is possible to visualize and record the effects of treatment as long as the surgeon knows what they are looking at but we feel it is also not appropriate to keep operating on people !	Thank you for your comment. The guideline will review both surgical and non-surgical management of endometriosis, the effects of treatment and prevention of disease recurrence.
Pelvic Pain Support Network	8	13-15	The issue is that women are NOT referred to a specialist and it takes multiple GP and/or A&E visits to get referred. We feel there should be a benchmark: see BPS Pelvic Pain Pathway for generalist care regarding length of time a person has experienced pain either intermittent or constant and the need for referral. We feel that a triage system would massively reduce delays in diagnosis and improve long term outcome.	Thank you for your comment. This text (section 3) is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. The issue of referral will be addressed as a key area (see scope sections 1.3.1, 1.3.2)
Pelvic Pain Support Network	8	20-22	We feel the fact that current treatments are contraceptive and often have unpleasant side effects is a major problem for many women with endometriosis. Pain and fertility/subfertility may be	Thank you for your comment which highlights the need for this guidance. We will include fertility as one of our outcomes and cross-reference to the NICE Fertility guideline.

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			of equal importance to many women.	
Pelvic Pain Support Network	8	28-29	We feel that the current geographic distribution of endometriosis centres around the country is unequal with the concentration of several centres in one relatively small area. Similarly we question the requirement of a BSGE Endometriosis centre to perform a small number of complex procedures each year regardless of the outcome for patients. Information about BSGE centre outcomes is currently not publicly available. We feel that there are transparency issues here and that this information should be publicly available in order for patients to be able to make an informed decision about by whom and where they are treated.	Thank you. This text (section 3) is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. We agree that service provision varies across the country. Therefore geographical area features in our equality impact assessment for this guideline. Publication of individual centres' data is not part of NICE's remit.
Pelvic Pain Support Network	8 3 9	3-4 29 4-5	It is not just that women think their doctors believe they are overreacting. We feel there is a major problem with a lack of knowledge about the assessment of pain amongst the medical profession. In addition we feel there is a serious cultural issue with many health professionals disbelieving young females when they present with pain and telling them the pain is psychological	Thank you for making these important points. Section 3 is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. There will be patient input to the guideline at all stages of development.

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			not physical. We feel this is a key reason why so many women are unhappy with their treatment and outcomes.	
Pelvic Pain Support Network	8	17	According to our survey data ultrasound is not systematically performed in those presenting with pain even prior to laparoscopy, let alone MRI. We feel that the extreme shortage of radiologists needs to be addressed urgently. This is a general point but is even more acute in this field.	Thank you for your comment. This text (section 3) is intended only as a brief outline of the problems which the Guideline will address. The use of imaging will be reviewed in the guideline (section 1.3.3) and a radiologist with special interest in pelvic imaging will be involved.
Pelvic Pain Support Network	9	4-5	We feel that this does not happen systematically even within an endometriosis centre. Women should be offered an annual review with a specialist endometriosis nurse to decide if they want to take this up if they have concerns they need to discuss. This is the case with asthma and many other long term conditions, why not with endometriosis ?it would flag up problems quicker, give women reassurance and access to expert care without the need to keep going to and from the GP to get re-referred and consequently saving the NHS money by reducing the number of needless appointments.	Thank you. This text (section 3) is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. We recognise the importance of monitoring long-term conditions and have identified this as a key area (section 1.3.2). A health economic analysis will be included.
RCOG	General	General	Comprehensive scope, suggest adding 'Auditable	Thank you for your comment. Auditable standards

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			standards' as required for NHS Healthcare and in keeping with RCOG Green Top Guidelines. Understandably, depends upon the remit of NICE guidelines.	are outside the remit of NICE guidelines. However, the recommendations and findings can inform audit programmes.
RCOG	2	1.1	Suggest adding 'confirmed ' as in women with confirmed endometriosis	Thank you for your comment. We have amended this e.g. 'women with confirmed or suspected endometriosis'
RCOG	2	1.1	We note that the guideline will not cover the management of women with endometriosis occurring outside the pelvis. We would have thought that a section on extra-uterine endometriosis would be useful; alternatively, the title of the guideline could be amended to 'Pelvic endometriosis: diagnosis and management'	Thank you for your comment. Endometriosis outside the pelvis was excluded from the scope because the prevalence of this is low and other key areas were prioritised accordingly.
RCOG	2 3	1.3	Include 'neuro modulators', and 'with and without oophorectomy' as in pg 4 line 18-23	Thank you for your comment. We have amended this accordingly.
RCOG	2 3	1.3	Key areas: 1. Suggest changing to: Symptoms and signs of endometriosis at the time of presentation 2. How and when to monitor and refer for complications and disease	Thank you. We have amended this to symptoms and signs. We do not agree that monitoring and referral would be better placed after the key area of treatment because we believe that this ought to occur

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			18 progression: This should ideally be placed after treatment: No 8 or 9	throughout the patient pathway.
RCOG	3 4	1.5	Feel 'at the time of presentation' is redundant. would suffice to say 'what are the symptoms and signs of endometriosis'	Thank you for your comment. We have amended this as well as the key area section accordingly
RCOG	3 4	1.5	Suggest adding in 'women with' as in ' how and when should women with endometriosis'	Thank you for your comment. We have amended this sentence accordingly.
RCOG	8	3.1	Sounds quite implicatory of GPs. Suggest rewording to a mellow tone as in ' many women with endometriosis believe that delays in diagnosis are due to healthcare professionals failing to recognise the significance of symptoms and think that women are over-reacting'. Would prefer to delete the sentence as it adds nothing major to the outcome.	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. This point was strongly voiced by patient groups, so we have not deleted it but have toned it down as suggested.
RCOG	8	3.2	Line 25: Surgical treatment is carried out in specialist endometriosis centres…… This is not factually correct. Surgical treatment like diathermy/excision of endometriosis is currently carried out in most hospitals. There is evidence of variation in the level of care that women experience in different geographical areas.	Thank you for drawing our attention to this. Section 3 is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. We have now changed 'surgical treatment' to 'complex surgical treatment' to highlight the difference between the types of surgery carried out in hospitals and those

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			Only **severe endometriosis** requiring multidisciplinary expertise is carried out in Specialist EM centres.	used in specialist endometriosis centres. We agree that service provision varies across the country. Therefore geographical area features in our equality impact assessment for this guideline.
Royal College of General Practitioners	General	General	A considerable number of women appear to have diagnostic delays in having their condition identified. Can the scope cover how to reduce the time to diagnosis?	Thank you for your comment. This problem has also been raised by patient groups. We agree that it is an important issue. Both clinical diagnosis (symptoms and signs) and diagnostic tests are addressed in the scope, and we hope that the recommendations will improve timely diagnosis.
Royal College of Nursing	2	9	*Women with endometriosis occurring outside the pelvis*: Would there be another guideline covering this? We think there should be some indication of which part of the healthcare system that this group will be directed to, otherwise, they have the potential to have inconsistent referrals to various specialities.	Thank you for your comment. The prevalence of endometriosis outside the pelvis is very low and NICE guidance should cover the majority of women with a condition. This topic was therefore not prioritised in the scope.
Royal College of Nursing	2	10	*Post-menopausal women*: Question why this group is being excluded? The exclusion of this group from the scope seems out of synch with the key fact regarding endometriosis.	Thank you for your comment. Management of post-menopausal women was not an area prioritised in the guideline scope, as NICE guidance on Menopause is in development. However, complications of surgical intervention will be

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			There is also no indication of how or where this group will access any help. This group could possibly have scarring and adhesions from untreated or previous surgical intervention from treatment in their 'younger years'.	covered.
Royal College of Nursing	2	11	*Settings:* We are pleased that the guidelines would be applicable in all settings in which NHS commissioned healthcare is provided. We consider that it would also be useful in all other settings and ask should these guidelines not apply to all settings not just NHS?	Thank you for your comment. NICE's remit is to provide guidance only for healthcare where NHS healthcare is provided or commissioned and we are limited by this. However, people providing healthcare in other settings may find the guideline useful.
Royal College of Nursing	3	6	*Information and support for women with endometriosis:* It would be useful to include some information on sexual health: We think there has to be some psychological support not only for the woman but also for their partners which would need to include the physical aspect of sexual intercourse too.	Thank you for your comment. We agree that this is an important issue. The scope is not intended to give a comprehensive list of information and support needs, but we have noted your points and will bring them to the attention of the committee when the detailed plan for the review is agreed.
Royal College of Nursing	3	8	*Investigation of fertility problems related to endometriosis:* Question why this is being excluded from the scope in view of the information contained in the key facts associated with	Thank you for your comment. We will include fertility as one of our outcomes and cross refer to the NICE Fertility guideline (CG 156).

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			endometriosis coupled with the proposal that fertility will be a main outcome of the guideline.	
Royal College of Nursing	3	20	*Key issues*: Could we include how to educate primary care professionals about this to reduce the length of time from onset to diagnosis?	Thank you. The training and education of primary care professionals is outside the remit of NICE guidance, but we hope that recommendations on symptoms and signs of endometriosis will improve timely diagnosis.
Royal College of Nursing	5	1	*Key issues – information and support:* Although mentioned, there is no specific information regarding support for the family, particularly partners/husbands. Our members have commented that they are aware of the impact endometriosis could have in relationships. In this regard it might be relevant to access information from this group of people to further inform on this part of the scope.	Thank you for your comment. We agree that this is an important issue. The scope is not intended to give a comprehensive list of information and support needs, but we have noted your points and will bring them to the attention of the committee when the detailed plan for the review is agreed.
Royal College of Nursing	7	2	A lot of key facts are not covered in this draft scope, so we would question the benefit of this work to the wider population. It seems a bit strange that within the context of key	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problem which the Guideline will address. It is therefore not a comprehensive summary of all aspects related to endometriosis. NICE guidance on

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			facts about endometriosis there is mention of endometriosis being mainly a disease of the reproductive years, but has been described in post-menopausal women. However, post-menopausal women are not being included, neither is management of menopausal symptoms related to surgical treatment of endometriosis. It also states in the key facts that information to date is based on prevalence studies of women presenting with one of several symptoms needing laparoscopy, for example, pelvic pain, dysmenorrhoea and subfertility, and that endometriosis is also an important cause of subfertility and this can also have a significant effect on quality of life, but the scope will not cover investigation of fertility problems related to endometriosis or care during pregnancy for women with endometriosis. Also fertility is listed as one of the main outcomes of this guideline. It just did not sound right that these issues were worthy of inclusion in key facts associated with	Menopause is in development. However, post-menopausal endometriosis has a low prevalence and NICE guidance is intended to cover the majority of perimenopausal and postmenopausal women. We will include fertility as one of our outcomes.

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			endometriosis but were not considered as key areas and aspects of care that would be covered in the scope of this guideline. It seems a missed opportunity.	
Royal College of Nursing	8	12	*Current practice:* The draft scope acknowledges the variation in practice and level of care that women experience in different geographical areas. Our members commented that some patients may have difficulties getting to these centres. There could also be variations in settings, choice and quality of pharmacological interventions and access to specialist healthcare professionals due to pressures on the NHS budgets. We hope that the guideline would seek to address these.	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. It is therefore not a comprehensive summary of all aspects related to endometriosis. Key areas in the scope address variation in pharmacological interventions and specialist services and the guideline will therefore seek to address these.
Royal College of Nursing	8	16, 17, 18	*Current practice*: An offer of a non-invasive method of diagnosis will be most women's first choice. How would this alternative to a diagnosis by laparoscopy impact on the already long waiting list for MRI scanning etc? How would priority be determined? It would be	Thank you for your comment. Non-invasive diagnostic methods will be reviewed in the guideline (see scope section 1.5.3)

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			useful to have guideline here.	
Royal College of Pathologists	General	General	The original scope draft document did mention endometriosis related cancers. I believe this needs to be retained in the final guideline, particularly to emphasise the need to have histological confirmation and assessment of any resected endometriotic tissue.	Thank you. The topic of histological confirmation is covered in the review questions (section 1.5.3). We have noted your comment and will raise it when the detailed plan for the review is drawn up with the committee.
Royal College of Pathologists	4	8	Endometrial biopsies would have no value in the management of endometriosis other than to exclude endometrial pathology as a source of symptoms that may be similar to those caused by endometriosis	Thank you for your comment. There are two studies that refer to the use of nerve fibre detection using proten gene product 9.5 as a marker and the diagnosis of endometriosis. The first published in Human Reproduction (Al-Jefout 2009) and the second in Arch Gynecol Obstet (Meibody 2011). For this reason, it has been included in the scope.
Royal College of Pathologists	4	9	Histological confirmation is absolutely necessary and whilst confirming the presence of endometriosis, the pathologist is able to exclude any endometriosis related pathology such as neoplastic transformation.	Thank you for your comment, which has been noted. We intend to invite a Histopathologist as an expert witness to the Committee.
Royal College of Pathologists	4	22	Any excision of endometriotic tissue should be confirmed by histology	Thank you for your comment, which has been noted.
Royal College of Pathologists	4	23	This NICE guidance should include a brief	Thank you for your comment, which has been

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			description of how to handle hysterectomy samples in cases of endometriosis. A pathologist should provide this description.	noted. We intend to include a Histopathologist as an expert witness to the Committee.
Self management uk	3 10	6	Within the area of information and support we believe that self-management programmes either group or on-line should be included. Self-management education covers areas such as: living with a long-term condition, belief systems own and those who support, exercise, healthy eating, relaxation, mindfulness, action planning, set back strategies, monitoring and partnership with healthcare team.	Thank you for your comment. We agree that these are important issues. The information and support needs that are reported in the literature will be summarised. At this stage, the scope is not intended to be a comprehensive list. We have noted your points and will bring them to the attention of the committee when the detailed plan for the review is agreed.
Self management uk	5 10	2/3	Within information and support for families and carers it is important that self-management education/programme is included as well as condition specific information.	Thank you for your comment. We agree that this is an important issue. The information and support needs that are reported in the literature will be summarised. At this stage, the scope is not intended to be a comprehensive list. We have noted your point and will bring it to the attention of the committee when the detailed plan for the review is agreed.
Self management uk	5	11/12	We believe that health related quality of life and activities of daily living can be support by self-management programmes. The self-management	Thank you for your comment. We agree that this is an important issue. In reviewing the evidence on information and support needs, outcomes will

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	10		approach contributes to achievement of NHS Outcomes Framework 2 – people will live full, active and independent lives with the priority being that people will be better able to cope with their condition. The self-management intervention is evidenced to enable attendees to make better day-to-day decisions about their condition and health that are meaningful to them. People participating in self-management show improved self-care behaviours, symptom control and problem-solving skills, which are linked to improved functional status, quality of life and reduced levels of difficult emotions such as stress or anxiety. They have a better understanding of the impact of an LTC and the risk factors and complications that can severely impact their day to day lives.	include health related quality of life and activities of daily living. We have noted your points and will bring them to the attention of the committee when the detailed plan for the review is agreed.
University of Oxford	2	9	How will we deal with extra-pelvic endometriosis? We should have a comment at least.	Thank you for your comment. The prevalence of endometriosis outside the pelvis is very low and NICE guidance should cover the majority of women with a condition. This topic was therefore not prioritised in the scope.
University of Oxford	2	10	How is menopause and endometriosis covered?	Thank you for your comment. Management of

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			We need to ensure it is well covered either in this guideline or in the menopause one. There is a significant unmet clinical-need for this.	menopause was not an area prioritised in the guideline scope, as NICE guidance on Menopause is in development.
University of Oxford	3	7	Is there scope for covering adenomyosis?	Thank you for your comment. We have not excluded adenomyosis co-occuring with endometriosis. However, we have excluded the management of adenomyosis in isolation because this falls outside the remit of an endometriosis guideline.
University of Oxford	3	8	There is insufficient advice/guidance in the fertility guidelines on endometriosis. I would suggest covering this in more detail in this guideline.	Thank you for your comment. We will include fertility as one of our outcomes and cross refer to the NICE Fertility guideline (CG 156).
University of Oxford	3	10	Would it be possible to include menopause as part of a NICE Clinical Guidance?	Thank you for your comment. NICE clinical guidance on Menopause is in development.
University of Oxford	4	2	Could we include history taking and clinical/pelvic exam?	Thank you for your comment. The proposed scope includes 'symptoms and signs' of endometriosis. We believe that 'history taking' and 'pelvic exam' is already the norm in current practice and it is therefore the added value of other diagnostic methods that is the focus of this question.
University of Oxford	4	14	I would possibly change 'laparoscopy' to 'diagnosis' as there are possibly other ways of	Thank you for your comment. This key question is 'timing of interventions' and we intended to review

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			diagnosing endometriosis.	laparoscopy in this context, as an intervention rather than diagnosis. We will try to clarify this when the detailed review questions are developed.
University of Oxford	4	17	The effect of HRT on recurrence, alleviation of symptoms and side effects needs to be included.	Thank you for your comment. HRT was not an area prioritised in the guideline scope, as NICE guidance on Menopause is currently in development.
University of Oxford	4	17	It is important to look at the clinical effectiveness of treatments not only in relative reduction of symptoms, but also in absolute terms (pain rating scale) to asses the need for additional treatment.	Thank you for your comment. At this stage, the outcomes stated in the scope are not a comprehensive list, and details of analysis and outcome scales will be agreed with the committee for each review topic. It is current process in NICE guidelines to favour considerations of absolute over relative effects.
University of Oxford	4	23	There are different ways of hysterectomy, which should be separately looked at.	Thank you. Different methods of hysterectomy are not excluded from this topic and can feature as a subgroup analysis; we will draw the committee's attention to your comment.
University of Oxford	4	27	Does non-medical therapy probably mean complimentary therapy?	Thank you for your comment. Complementary therapies will be included but we believe that not all 'non-medical' management can be classed as 'complementary'.
University of Oxford	4	30	This will be quite political, still very important to	Thank you for your comment, which we have noted.

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			evaluate. Also, the referrers need to know the referral pathway/indication to refer a patient to a specialist endometriosis centre.	A care pathway will be developed.
University of Oxford	5	1	Include potential co-morbidities	Thank you for your comment. We will include your point when developing the detailed review questions.
University of Oxford	5	10	Subcategorize pain into e.g. dyspareunia, dysmenorrhea, dyschesia, dysuria, cyclical and non-cyclical pain.	Thank you for your comment. We will include your point when developing the detailed review questions.
University of Oxford	5	14	Change 'Recurrence of endometriosis' to 'Recurrence of endometriosis symptoms'.	Thank you for your comment. All of the outcomes in this section are left deliberately broad. We will provide detailed descriptions of outcomes for each topic in a comprehensive plan for each review question.
World Endometriosis Research Foundation	2	9	Will there be a short paragraph acknowledging endometriosis outside of the pelvis and perhaps refer to a NICE Clinical Guidance on the matter?	Thank you for your comment. Endometriosis outside the pelvis was excluded from the scope because the prevalence of this is low and other key areas were prioritised accordingly.
World Endometriosis Research Foundation	2	10	Menopause is very complex in women with endometriosis. Unless this is covered specifically in the NICE Guideline on the Menopause we would propose that a section is dedicated to this in	Thank you for your comment. Management of menopause was not an area prioritised in the guideline scope, as NICE guidance on Menopause is in development.

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			the NICE Endometriosis Guideline.	
World Endometriosis Research Foundation	2	17	Propose a re-wording to: How to monitor disease progression and when (and where) to refer to an endometriosis specialist	Thank you for your suggestion. We believe that 'when' applies not only to referral but also to monitoring. Use of specialist services is another key area and if agreed with the committee timing will be taken into consideration for this topic.
World Endometriosis Research Foundation	2	21	Propose a re-wording to: Validity and usefulness of the current staging systems when making clinical treatment decisions	Thank you for your comment. We agree that this is important and information which will usually be extracted if and when it is reported in primary studies. However, we will not carry out validations of individual systems and therefore will not add validity explicitly to the scope document.
World Endometriosis Research Foundation	3	10	As above: the management of menopausal symptoms (surgical and natural) is a complex matter, which perhaps can be addressed in a NICE Clinical Guidance to which the Guideline can refer?	Thank you for your comment. Management of menopausal symptoms was not an area prioritised in the guideline scope for Endometriosis, as NICE guidance on Menopause is in development. We will pass your comment on to the NICE Topic selection panel.
World Endometriosis Research Foundation	3	11	Adenomyosis and endometriosis are becoming increasingly interlinked. As above: perhaps this could be addressed and referred to in a NICE Clinical Guidance?	Thank you for your comment. We have not excluded adenomyosis co-existing with endometriosis. However, we have excluded the management of adenomyosis in isolation because this falls outside the remit of an endometriosis

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				guideline.
World Endometriosis Research Foundation	3	8 – 9	Unless the NICE Guideline on Infertility specifically focuses on women with endometriosis, we would propose this should be included in this guideline – not least when it comes to caring for women whilst pregnant, as new evidence has proven their pregnancies can be a lot more complicated.	Thank you for your comment. Fertility will be covered as one of the outcomes. However, the care of women with endometriosis during pregnancy was not prioritised in the guideline scope.
World Endometriosis Research Foundation	3	24	Add: "the age", ie. "What are *the age*, the symptoms and signs…."	Thank you for your comment. The focus of this question is the type of symptoms and signs that are common rather than at what age they specifically occur. We will be considering a wide age range; only postmenopausal women are excluded from the guideline.
World Endometriosis Research Foundation	3	28	Rephrase to: "…and complications, *and when and where to refer to specialists*, including:"	Thank you for your comment. We have added 'and referred' to monitored. We did not want to be too specific about where they would be referred to.
World Endometriosis Research Foundation	3 5	29 10	Since different types of pain may indicate different types of disease – and consequent disease management – it is important to focus on each of the types of pain, ie: dysmenorrhea, dyspareunia, dyschezia, dysuria, etc…..	Thank you for your helpful comment. We will include your point when developing the detailed review questions.
World Endometriosis	4	3	Add: "Patient history" and "Pelvic exam" to the list	Thank you for your comment. The proposed scope

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Research Foundation			of potential tests for diagnosing endometriosis	includes 'symptoms and signs' of endometriosis which will cover patient history and pelvic exam.
World Endometriosis Research Foundation	4	14	Since the guideline has not yet established the "gold standard" for diagnosis is "laparoscopy", we would propose this is rephrased to: "Does early *diagnosis* and treatment improve outcomes?"	Thank you for your comment. This key question is 'timing of interventions' and we intended to review laparoscopy in this context, as an intervention rather than diagnosis. We will try to clarify this when the detailed review questions are developed.
World Endometriosis Research Foundation	4	16 25	It is important to acknowledge that most treatments may be effective but that that effectiveness may be very little or for a short time. It is therefore imperative that we ask to what extent these treatments are effective. We propose this is rephrased to "What is the *extent of the* effectiveness of…."	Thank you for your comment. The word extent implies that we are certain that they are effective already. We believe there is uncertainty in clinical practice and will therefore not amend this.
World Endometriosis Research Foundation	4	23	There is presently a lot of debate about how hysterectomies are carried out, so would propose a rephrase to: "*Surgical mode of* hysterectomy, with……" and that a question is added addressing the use of HRT post-hysterectomy	Thank you for your comment. We did not want to be too restrictive in the scope but different methods of hysterectomy are not excluded from this topic and can feature as a subgroup analysis; we will draw the committee's attention to your comment.
World Endometriosis Research Foundation	4	27	The phrase "non-medical" can mean a lot of things. We propose that this is changed to *complementary therapies* throughout the document as is standard now in other guidelines	Thank you for your comment; we believe that not all 'non-medical' management can be classed as 'complementary'.

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World Endometriosis Research Foundation	4	30	Add this very important question: *What is the clinical criteria and definition for being referred to an endometriosis centre of expertise (specialist care)?*	Thank you for your comment. This will be addressed in the review questions on referral and specialist services.
World Endometriosis Research Foundation	5	1	There's an increased worry among women with endometriosis about co-morbidities, so we propose that this question is added: *What are the short- and long-term risks of developing co-morbidities, including sub-fertility, pre-eclampsia, and cancer?*	Thank you for your comment. We agree that co-morbidities are important and will address your point when developing the detailed review questions.
World Endometriosis Research Foundation	5	14	Since there is no evidence that the mere presence of endometriosis causes symptoms, we propose this is rephrased to: "recurrence of *symptoms of* endometriosis *with and without evidence of endometriotic lesions (disease pathology)*"	Thank you for your comment. All of the outcomes in this section are left deliberately broad. We will provide detailed descriptions of outcomes for each topic in a comprehensive plan for each review question.
World Endometriosis Research Foundation	7	10 - 14	It would be very interesting to see the references that back up these claims?	The cost of inpatient treatment for endometriosis in Germany in 2006 published in Gynaecological Endocrinology (Oppelt et al. 2012) estimated the average cost per patient at 3056 Euros. A total of 20,835 women were admitted to Hospital in 2006 for endometriosis treatment (1.27 women per 1000 reproductive age women). The total inpatient costs for endometriosis treatment in 2006 were estimated

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				at 40,708,716 Euros. The operation most often performed in treating endometriosis was hysterectomy in 24.7% of cases.
World Endometriosis Research Foundation	7	24 - 25	Are 2nd look laparoscopies still being used to monitor treatment effectiveness? If not, perhaps this last sentence in this paragraph should be removed?	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problem which the Guideline will address.This does not imply second-look laparoscopies are used to monitor treament effectiveness.
World Endometriosis Research Foundation	7	5	Since the aetiology and pathogenesis of endometriosis are unknown, this should be changed to: "…growth of endometrial *like* tissue. *Whereas the* cause *is unknown, theories include* metaplasia……"	Thank you. Section 3 is part of the background to the scope and intended only as a brief outline of the problem which the Guideline will address. It is therefore not a comprehensive summary of all aspects related to endometriosis.
World Endometriosis Research Foundation	8	24	Propose a small change to: "…of management of pain *and/*or fertility"	Thank you. We have amended this accordingly
World Endometriosis Research Foundation	8	25	Surgical treatment is currently <u>not</u> carried out in specialist endometriosis centres, so perhaps this sentence should be rephrased to: "Surgical treatment *should be* carried out….." and add *colorectal* to the multidisciplinary team.	Thank you for drawing our attention to this. Section 3 is part of the background to the scope and intended only as a brief outline of the problems which the Guideline will address. We cannot judge what 'should be' done until the evidence is reviewed. However, We have now changed 'surgical treatment' to 'complex surgical treatment'

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				to highlight the difference between the types of surgery carried out in hospitals and those used in specialist endometriosis centres. The list of multidisciplinary team members is not comprehensive in this sentence, but we will invite a colorectal surgeon as an expert witness for guideline development.
World Endometriosis Research Foundation	9	19	We would be very interested in seeing the reference for this claim, please?	Thank you for your comment. The reference here is Oppelt et al. 2012. Section 3 is part of the background to the scope and intended only as a brief outline of the problem which the Guideline will address. It is therefore not presented as a scientific review with references.