

Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
British Dietetic Association - Maternal and Fertility Specialist Group	Table	1.11	Please consider referral to Registered Dietitian prior to consideration of surgery as dietary management could have an impact on symptom management and potentially help reduce surgical burden. It could also provide a window to improve good preconception practices amongst this cohort with high incidence of disordered eating and restrictive food behaviour ^{1,2} . Interventions with low FODMAP diet (which is best delivered dietitian led) has shown to improve visceral hypersensitivity in 72% of individuals who presented with endometriosis and functional gut symptoms ³ . Dietary modifications such as altering quantity and kind of fibre and increasing intake of omega fatty acids have shown to improve pain scores and menstrual cyclicity ⁴ . Though this is a growing area of research and practice for registered dietitians it provides a low cost, non-invasive, evidence-based approach to help support the individuals with endometriosis with effective symptom management and fertility and preconception lifestyle practices. HCPC Registered Dietitians are the only nutritional professionals regulated by law in the UK and governed by an ethical code to ensure they always work to the highest standard.	Thank you for your comment. Dietary interventions were included as an intervention of interest however no evidence that met the inclusion criteria for the review was identified and so the committee was not able to make recommendations for dietary management. The studies you have listed were not included as they are either a retrospective analysis, online questionnaire or qualitative interviews and so did not meet the protocol criteria of systematic reviews of randomised controlled trials or randomised controlled trials.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document Line No	Comments	Developer's response
		References: 1. Deepak Kumar K, Appleby-Gunnill B, Maslin K. Nutritional practices and dietetic provision in the endometriosis population, with a focus on functional gut symptoms. J Hum Nutr Diet. 2023 Aug;36(4):1529-1538. doi: 10.1111/jhn.13158. Epub 2023 Mar 9. PMID: 36794746. 2. Deepak Kumar K, Narvekar NN, Maslin K. Self-managed dietary changes and functional gut symptoms in endometriosis: A qualitative interview study. Eur J Obstet Gynecol Reprod Biol X. 2023 Jul 22;19:100219. doi: 10.1016/j.eurox.2023.100219. PMID: 37575367; PMCID: PMC10413417. 3. Moore JS, Gibson PR, Perry RE, Burgell RE. Endometriosis in patients with irritable bowel syndrome: Specific symptomatic and demographic profile, and response to the low FODMAP diet. Aust N Z J Obstet Gynaecol. 2017; 57: 201–205. Karlsson JV, Patel H, Premberg A. Experiences of health after dietary changes in endometriosis: a qualitative interview study. BMJ Open. 2020; 10:e032321	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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British Society of Lifestyle Medicine	EIA		Please consider some religious/ belief system that may have an impact on women coming forward to discuss these issues or affecting their choice of hormonal treatment to trigger menopause.	Thank you for your comment. The EIA already recognises that people from some ethnic groups may face additional barriers when talking about menstrual health, and people from some different religious/belief systems have now been added as well.
British Society of Lifestyle Medicine	Table	3	I am concerned there is not enough evidence reviewed that relates to lifestyle factors that contribute to fertility, enough for women to be able to make informed decision about their care. Understandably, this could be due to insufficient evidence specifically in this sphere. Please consider the positive role prehabilitation may have on the outcome of the surgery.	Thank you for your comment. Prehabilitation was not included as an intervention in the predefined protocol for this review. A number of the individual interventions which form part of prehabilitation (diet, exercise, activities to improve wellbeing) were included in the protocol but no evidence that met the protocol criteria was identified. It was therefore not possible to identify if prehabilitation or its components improved spontaneous pregnancy rates. The committee made a research recommendation relating to combinations of hormonal and surgical treatment as they agreed this was where there was most uncertainty but did not prioritise a research recommendation relating to prehabilitation. There is a NICE guideline on perioperative care in adults (NG180, August 2020) which already contains some limited recommendations on enhanced recovery programmes and it is likely that if further research



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
				prehabilitation becomes available it would be picked up in any future updates to NG180
Endometriosis Guidance and Information Resource UK	Table	1	Endometriosis: Diagnosis and management (NG73) – Update to recommendations on treatment if fertility is a priority, page 3. Proposed revised recommendation, Management if fertility is a priority,1.11, lines 5-10. It is recommended that 'the management of endometriosis-related subfertility should have multidisciplinary team involvement with input from a fertility specialist'. Depending on the severity of an individual's endometriosis, as diagnosed by imaging or surgery, this team might be in secondary care or in a tertiary specialist centre. For those with severe endometriosis who fulfil the referral criteria laid down in the NHS England treatment specification for severe endometriosis (link below) the first point of referral will be direct to a specialist centre for pain and/or subfertility. We ask for consideration of the additional statement 'this team might be within a secondary care gynaecology department or a specialist tertiary endometriosis centre depending on severity of disease which might impact the overall treatment plan and not just for subfertility.'	Thank you for your comment. This over-arching information statement has been amended to include the fact that the multidisciplinary team may be in a secondary care gynaecology service or a tertiary care specialist endometriosis service, as you suggest.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/e10-comp-gynae-endom-0414.pdf We do not consider that it would be challenging to implement this recommendation.	
Endometriosis Guidance and Information Resource UK	Table	1	Endometriosis: Diagnosis and management (NG73) – Update to recommendations on treatment if fertility is a priority, page 3. Proposed revised recommendation, Management if fertility is a priority, 1.11.1, lines 4-5. It is recommended to 'offer excision or ablation of endometriosis plus adhesiolysis for endometriosis not involving the bowel, bladder or ureter'. The reference to 'bowel, bladder or ureter' appears to be taken from the current NICE guideline NG73, 1.4.2, when advising which women should be referred to a specialist endometriosis centre. In producing the current guideline this appears to have been drawn from an incorrect section of the ESHRE guideline in force at the time, being the 2013 version, 1.3.7 (link below). This recommended 'that clinicians should assess ureter, bladder and bowel involvement by additional imaging if there is suspicion based on history or physical	Thank you for your comment. This recommendation relates to management of superficial or mild endometriosis and does not imply that that this recommendation provides a complete and accurate definition of deep endometriosis. It is based on the evidence review conducted in 2017 which found that surgery in women with superficial endometriosis (which would not, by definition, involve the bowel bladder or ureter) improves the chances of spontaneous pregnancy. This recommendation was not amended based on the evidence from the updated review because there was no new evidence identified for this strata (new evidence was identified for ovarian disease/endometrioma, ovarian deep not involving other structures, ovarian/peritoneum deep involving other structures, or unclear strata). In addition, despite the fact that the NHS service specification uses the term 'deeply infiltrating' the committee agreed that this term was not widely used



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			examination of deep endometriosis'. This clearly intended to recommend pre-lap assessment by imaging of retroperitoneal disease and not to describe deep endometriosis itself in its entirety. Deep endometriosis was separately described at 2.4.5 as 'deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder or ureter'. This is broadly in line with the description of severe endometriosis in the NHS England treatment specification for treatment of severe endometriosis (link below), that is laid down in legislation (Health and Social Care Act, 2012), and which was published for the first time in the same year, 2013. In the same section of the ESHRE guideline 2013 that gave the full description of deep endometriosis (1.3.7), the recommendation by the GDC was 'that clinicians refer women with suspected or diagnosed deep endometriosis to a centre of expertise that offers all available treatments in a multidisciplinary context'. It is clear that referral to endometriosis centres was not just for retroperitoneal disease affecting the bowel, bladder and ureter as stated in the NICE guideline, but for all presentations of	anymore as it has connotations with cancerous conditions and could cause undue stress to women and people with endometriosis. Therefore, the language in this recommendation has not been amended. However, changes have been made to the later recommendation which refers more directly to deep endometriosis and we have responded to your comments on this separately. The committee noted your comment that there may be a discrepancy between the definitions of deep endometriosis used by NICE and used in the NHS England service specification but as you have informed us, the service specification is currently being revised. It will therefore be flagged to the surveillance team at NICE that the guideline may need updating when the revised specification is in place to ensure the documents do not contradict each other.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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		deep endometriosis as described. In the context of running a guidance group for women with endometriosis our members have been able to rely on the NHS England specification for the purposes of defining referral criteria for acceptance into endometriosis centres, but those relying on the NICE guideline, including those in devolved boards, have been greatly disadvantaged by the incomplete description of severe endometriosis that allows only for cases of retroperitoneal disease to be referred to centres and not the classic stage 4 cases involving an obliterated pouch of Douglas, uterosacral ligaments, cervix/vagina and deep ovarian involvement with or without bowel, bladder or ureteral infiltration. We have previously notified NICE of this, but unfortunately were not stakeholders at the time of the 2022 surveillance review so could not comment formally. It does seem vital that all references to 'bowel, bladder and ureter' when referencing deep endometriosis in NICE literature, including all other affected sections of the updated guideline, are corrected and brought in line with the NHS England definition. We ask for consideration of a revised	
			of running a guidance group for women with endometriosis our members have been able to rely on the NHS England specification for the purposes of defining referral criteria for acceptance into endometriosis centres, but those relying on the NICE guideline, including those in devolved boards, have been greatly disadvantaged by the incomplete description of severe endometriosis that allows only for cases of retroperitoneal disease to be referred to centres and not the classic stage 4 cases involving an obliterated pouch of Douglas, uterosacral ligaments, cervix/vagina and deep ovarian involvement with or without bowel, bladder or ureteral infiltration. We have previously notified NICE of this, but unfortunately were not stakeholders at the time of the 2022 surveillance review so could not comment formally. It does seem vital that all references to 'bowel, bladder and ureter' when referencing deep endometriosis in NICE literature, including all other affected sections of the updated guideline, are corrected and brought in line with the NHS England



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			endometriosis' with a numbered reference to the NHS England treatment specification.	
			In this connection we wish to bring attention to the fact that the NHS England treatment specification is currently under review and the draft of the new version is not yet out for consultation. As a stakeholder a request has been made that clarification is given in the new specification as to which endometrioma cases should be referred to specialist endometriosis centres when not accompanied by rectovaginal disease (some stage 3 cases). The NHS England definition of severe endometriosis does include deep infiltrating endometriosis of the ovary, so clarity is needed as to when such endometriomas should be referred to centres based on, for example, size/complexity, location in the ovary, pregnancy wish. Since it is likely that this revised NICE guideline will be published before the new NHS England specification is available it might be necessary to make changes once the latter is	
			published. The incompleteness of 'bowel, bladder and ureter' seems to be further borne out by the evidence	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			review document on page 30 'Analysis of subgroups'. Under the strata based on severity of disease, the most severe is described as 'deep involving other structures – bladder, rectovaginal, bowel involvement, ureter' which does not tally with this recommendation and highlights the importance of rectovaginal disease in considering treatment options.	
			2013 ESHRE guideline: https://guidelines/Endometriosis/ESHRE-guideline-on-endometriosis-2013.pdf NHS England treatment specification for severe endometriosis 2013: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/e10-comp-gynae-endom-0414.pdf	
			We do not consider that it would be challenging to implement this recommendation as it stands as no change is proposed. However, correcting the error identified is likely to be challenging in terms of time and cost but for the sake of accuracy, consistency and safety of women (which we consider paramount for a NICE guideline) seeking	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			referral to endometriosis centres based on the correct referral criteria we feel the benefit must outweigh any challenge.	
Endometriosis Guidance and Information Resource UK	Table	3	Endometriosis: Diagnosis and management (NG73) – Update to recommendations on treatment if fertility is a priority, page 4. Proposed revised recommendation, Management if fertility is a priority 1.11.3, lines 6-7. It is recommended to discuss the benefits and risks of laparoscopic surgery as a treatment option with women or people who have deep endometriosis involving the bowel, bladder or ureter and who are trying to conceive. The reference to bowel, bladder and ureter appears to be taken from the current NICE guideline, NG23, 1.4.2, when advising which women should be referred to a specialist endometriosis centre. In producing the current guideline this appears to have been drawn from an incorrect section of the ESHRE guideline in force at the time, being the 2013 version, 1.3.7 (link below). This recommended 'that clinicians should assess bowel, bladder and ureter involvement by additional imaging if there is a suspicion based on history or physical examination of deep endometriosis'. This clearly	Thank you for your comment which we note is the same as the comment you have made in relation to recommendation 1.11.1. The committee amended the wording in this recommendation to clarify that it relates to people with deep endometriosis, including that involving the bowel, bladder or ureter, to address your concerns that it excludes some sites of deep endometriosis. Despite the fact that the NHS service specification uses the term 'deeply 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. The committee noted your comment that there may be a discrepancy between the definitions of deep endometriosis used by NICE and used in the NHS England service specification but as you have informed us, the service specification is currently being revised. It will therefore be flagged to the surveillance team at NICE that the guideline may need updating when the revised specification is in



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			intended to recommend pre-lap assessment by imaging of retroperitoneal disease and not to describe deep endometriosis itself in its entirety. Deep endometriosis was separately described at 2.4.5 as 'deep endometriosis extends beneath the peritoneum and may affect the uterosacral ligaments, pelvic side walls, rectovaginal septum, vagina, bowel, bladder or ureter. This is broadly in line with the description of severe endometriosis in the NHS England treatment specification for the treatment of severe endometriosis (link below), that is laid down in legislation (Health and Social Care Act, 2012), and which was published for the first time in that same year, 2013. In the same section of the ESHRE guideline 2013 that gave the full description of deep endometriosis (1.3.7), the recommendation by the GDC was 'that clinicians refer women with suspected or diagnosed deep endometriosis to a centre of expertise that offers all available treatments in a multidisciplinary context'. It is clear that referral to endometriosis centres was not just for retroperitoneal disease affecting the bowel, bladder or ureter as stated in the NICE guideline, but for all presentations of deep endometriosis as described. In the context of running a guidance	place to ensure the documents do not contradict each other.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			group for women with endometriosis, our members have been able to rely on the NHS	
			England specification for the purposes of defining	
			referral criteria for acceptance into endometriosis	
			centres, but those relying on the NICE guideline,	
			including those in devolved boards, have been	
			greatly disadvantaged by the incomplete	
			description of severe endometriosis that allows	
			only for cases of retroperitoneal disease to be	
			referred to centres and not the classic cases of	
			stage 4 endometriosis involving an obliterated pouch of Douglas, uterosacral ligaments,	
			cervix/vagina and deep ovarian involvement,	
			without bowel, bladder or ureteral infiltration. We	
			have previously notified NICE of this but	
			unfortunately were not stakeholders at the time of	
			the 2022 surveillance review so could not	
			comment formally. It does seem vital that all	
			references to 'bowel, bladder and ureter' when	
			referencing deep endometriosis in NICE literature,	
			including all other affected sections of the	
			updated guideline, are corrected and brought in	
			line with the NHS England legal definition. We ask	
			for consideration of a revised description 'deep	
			infiltrating and/or rectovaginal endometriosis' with	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			a numbered reference the NHS England treatment specification.	
			In this connection we wish to bring attention to the fact that the NHS England specification is currently under review and the draft of the new specification is not yet out for consultation. As a stakeholder a request has been made that clarification is given in the new specification as to which endometrioma cases should be referred to specialist endometriosis centres when not accompanied by rectovaginal disease (some stage 3 cases). The NHS England definition of severe endometriosis does include deep infiltrating disease of the ovary, so clarity is needed as to when such endometriomas should be referred to centres based on, for example, size/complexity, location in the ovary, pregnancy wish. Since it is likely that this new NICE guideline will be published before the revised NHS England	
			specification is available, it may be necessary to make changes once the latter is published.	
			2013 ESHRE guideline:	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			on-endometriosis-2013.pdf NHS England treatment specification for severe endometriosis 2013: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2014/04/e10-comp-gynae-endom-0414.pdf	
			The incompleteness of 'bowel, bladder and ureter' seems to be further borne out by the evidence review on page 30 'Analysis of sub-groups'. Under the strata based on severity of disease, the most severe is described as 'deep involving other structures – bladder, rectovaginal, bowel involvement, ureter' which does not tally with this recommendation and highlights the importance of rectovaginal disease in considering treatment options.	
			We do not consider that it would be challenging to implement this recommendation as it stands, but correcting the error identified is likely to be challenging in terms of time and cost but for the sake of accuracy, consistency and safety of women (which we consider paramount for a NICE guideline) seeking referral to endometriosis	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			centres based on the correct referral criteria we feel the benefit must outweigh the challenge.	
Endometriosis Guidance and Information Resource UK	Table	3	Endometriosis: Diagnosis and management (NG73) – Update to recommendations on treatment if fertility is a priority, page 4/5. Proposed revised recommendation, Management if fertility is a priority 1.11.3, lines – comment as a whole. Although some women with severe endometriosis will have retroperitoneal infiltration of the bowel, bladder or ureter, the classic stage 4 presentation will usually be of an obliterated pouch of Douglas, with the cervix/vagina densely adherent to the rectum. An ovary (most often the left) will typically contain large endometriomas and be bound by dense fibrosis to the rectovaginal complex. Both ovaries might be involved and drawn round to the back of the uterus (kissing) resulting in a frozen pelvis. Whilst the recommendation does include discussing the benefits and risks of laparoscopic surgery as a treatment option, the examples given just relate to fertility. We are concerned that in such cases of severe disease the risks are not just limited to operating and consequences of that on fertility; there can be great risks to not operating where	Thank you for your comment. The committee discussed your comment and agreed that there was evidence of pregnancy complications with endometriosis, but that there was no evidence that surgery to improve fertility would prevent all these complications. However, the committee agreed to add an additional bullet to this recommendation to state that the impact of endometriosis on pregnancy outcomes should be discussed.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			pregnancy is sought. Most with such severe disease are likely to be in pain and choose surgery anyway, but we see many women being referred to fertility services with very severe endometriosis being advised to pursue IVF rather than surgery. In this scenario a pregnancy can to be extremely painful with potential for significant complications as a pregnancy develops and for delivery. We feel that although this guideline is concerned with fertility, this aspect of surgery can't be ignored. We suggest that an additional example topic might be added 'the potential complications of a pregnancy in the presence of severe deep infiltrating and/or rectovaginal disease'.	
			implement this recommendation.	
Endometriosis Guidance and Information Resource UK	Table	3	Endometriosis: Diagnosis and management (NG23) – Update to recommendations on treatment if fertility is a priority. Page 4. Proposed revised recommendation, Management if fertility is a priority, 1.11.3, lines 8-9. The recommendation to discuss benefits and risks of laparoscopic surgery as a treatment option for	Thank you for your comment. Based on your previous comment on the introductory text at the start of this section of the guideline, the committee had already added over-arching advice about the availability of a multidisciplinary team, access to fertility services and fertility specialists, and the need for care in a tertiary care specialist endometriosis



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			these severe cases refers only to 'working with a fertility specialist'. Women with identified severe endometriosis (correctly defined) should be referred to a specialist endometriosis centre in accordance with 1.4.2 of the NICE guideline and the NHS England treatment specification. These centres must have access to fertility services (NICE guideline 1.1.4). It necessarily follows that such women should be seen in specialist endometriosis centres, whether or not pain is a significant factor. We believe that the complexity of surgery and discussions around it for severe endometriosis, whether for pain and/or fertility, can only be made by a multidisciplinary team in an endometriosis centre, including fertility services as part of that wider team. We suggest that 'working with a fertility specialist' be amended to 'working with a multidisciplinary team in a specialist endometriosis centre, including access to fertility services'. We do not consider that it would be a challenge to implement this recommendation.	service depending on the severity of endometriosis, so they did not add the same text to this recommendation as well.
Endometriosis UK	Table	1	Endometriosis UK are pleased that the section heading has changed to cover management of	Thank you for your comment.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			endometriosis. We agree that this section should be inclusive of other management options and not just surgical management.	
Endometriosis UK	Table	1	Considering current guidelines for cryopreservation of oocytes and embryos within NICE's guideline, fertility problems: assessment and treatment (CG156). Endometriosis UK asks that you consider increasing the scope for fertility preservation for those with endometriosis where there is a risk of decline in ovarian reserve with management/treatment. Or in cases where there is a possible impact to ovarian reserve in terms of anti-Mullerian hormone levels, ovarian volume and antral follicle count. Within this guideline the inclusion criteria for cryopreservation is exclusively for people with cancer who wish to preserve fertility (1.16). We ask that the criterion for cryopreservation is reviewed as part of the update to recommendations on treatment of endometriosis if fertility is a priority.	Thank you for your comment. The NICE guideline on Fertility problems: assessment and treatment is currently being updated and the section on fertility preservation is being updated to include other conditions, as well as cancer. Please see https://www.nice.org.uk/guidance/gid-ng10263/documents/final-scope
Endometriosis UK	Table	2	Endometriosis UK are pleased that the recommendation for laparoscopic ablation and drainage for people with endometrioma has been added as another treatment option for those	Thank you for your comment.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			where there is a possible impact to ovarian reserve. Although excisional surgery is often the recommended technique for surgical management, where there is risk of decline in ovarian reserve with endometrioma, laparoscopic ablation and drainage may present a suitable treatment to preserve ovarian reserve more than laparoscopic cystectomy.	
FTWW: Fair Treatment for the Women of Wales	EIA	3.4	Regarding barriers to, or difficulties with, access for a specific group: Here 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 this section of the guidance pertains to conversations about benefits and risks of a particular course of action, informed choice, and shared decision-making, ensuring these needs are considered and accommodated is vitally important. We would also suggest that some reference to geographical barriers and inequities might be made, not least as patients in some parts of the	Thank you for your comment. These extra considerations have been added to the EIA. Making reasonable adjustments to communication for people with conditions such as a learning disability or autism as required by the Equality Act is a statutory requirement and so this requirement would not be repeated in each individual NICE guideline. The section of the guideline on organisation of care already includes recommendations on the community, gynaecology and specialist endometriosis services that should be commissioned and provided for women or people with suspected or confirmed endometriosis. However, as NICE guidelines cover health and care in England, decisions on how they may apply in other UK countries are made by ministers in the Welsh



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			UK will have more difficulty accessing specialist endometriosis and associated fertility services due to their location. This may well impact on the type of treatment offered and time-scales to accessing it.	Government, Scottish Government and Northern Ireland Executive.
FTWW: Fair Treatment for the Women of Wales	EIA	3.5	We would ask that the Committee consider using social model language as far as possible – preferred terminology includes 'disabled people' and 'impairments' (rather than 'people with disabilities').	Thank you for your comment. The NICE style is to use the terminology 'people with' and so this has not been changed.
FTWW: Fair Treatment for the Women of Wales	EIA	3.6	Please see above re 3.4 and 3.5	Thank you for your comment. The issues you have raised in relation to section 3.4 and 3.5 of the EIA have been added to the post-consultation section of the EIA (4.1).
FTWW: Fair Treatment for the Women of Wales	General	n/a	We would welcome clarity on whether this section of the guidance is to be called 'Management of Endometriosis where Fertility is a Priority' or 'where Fertility is a Problem' as both terms appear interchangeably throughout the published information and documentation.	Thank you for your comment. The correct terminology is 'when fertility is a priority' and all the guideline documents use this wording. The use of the terminology 'problem' was an error on the consultation webpage for which we apologise.
			Example here: https://www.nice.org.uk/guidance/indevelopment/	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			gid-ng10393/consultation/html-content-5 2. Read the consultation documents Documents to comment on: Update to recommendations on Endometriosis: diagnosis and management – surgical management if fertility is a problem	
FTWW: Fair Treatment for the Women of Wales	Table	1	Whilst there has been no change made here, we would like to take the opportunity to reiterate our concerns about the original (2017) recommendation, where there is no differentiation between excision and ablation. We believe it is essential to elaborate on why excision is favourable, and to describe the circumstances under which a more conservative approach (involving ablation) might be preferable. It is important to note that presence of endometrioma is often associated with deep infiltrating endometriosis (DIE) affecting bowel, bladder, and ureters, alongside adhesion formation. Adhesions can impact pelvic anatomy to the extent that fertility is compromised. Meanwhile, severe and / or DIE is also associated with inflammation of the pelvic structures,	Thank you for your comment. As you have noted, this recommendation has not been updated as no new evidence was identified for the treatment of superficial endometriosis. The evidence previously identified in 2017 did not provide information to allow the committee to make recommendations on the circumstances in which excision or ablation would be preferable for superficial endometriosis. The committee agreed that the decision of how to treat the endometriosis should be based on its depth, and the subsequent recommendations provide advice on the treatment of endometriomas and deep endometriosis, which would be managed in a tertiary specialist endometriosis service, and where necessary expertise would be available to determine the most appropriate surgical technique.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			potentially leading to altered immune system functioning. This, in itself, is an unfavourable environment for pregnancy.	
			Observational follow-up studies and anecdotal evidence suggest that in cases of endometrioma and DIE affecting bowel, bladder, and ureters, excision surgery alongside adhesiolysis, offers patients the best chance of improved fertility, quality of life, and reduced symptoms. This is an important consideration if the purpose of the guideline is to improve patient outcomes, improve efficiency, and reduce unnecessary waste in the healthcare system.	
			Whilst we understand the Committee's wish to not be too prescriptive about the offer of excision rather than ablation (because there are some types of lesions that would necessitate one approach over the other), we would argue that there is a need to define more clearly where these instances would arise and not assume that regular gynaecology settings are equipped to differentiate. We would advise that, where patients meet the criteria of DIE (alongside endometrioma), they be referred to tertiary	



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

Stakeholder	Document	Line No	Comments	Developer's response
			endometriosis centres for more specialised and multi-disciplinary care, including fertility services where applicable.	
			It is also worth pointing out that patients who go on to successfully conceive and give birth may find that symptoms return more quickly following a surgery involving ablation rather than excision. In those circumstances, it seems unrealistic and burdensome to both patient and healthcare provider to create a situation where new mothers may to have to re-enter the healthcare system for further surgery when this may have been avoided had a more optimal approach been utilised in the first instance.	
FTWW: Fair Treatment for the Women of Wales	Table	2	We believe that NICE guidance should take more account of patient trajectory and likelihood of need for further health interventions if a particular course of action is taken. With that in mind, we would caution against 'ablation and drainage of ovarian endometriomas' being offered as an equivalent to cystectomy, especially where the latter also includes expert excision of endometriosis lesions elsewhere.	Thank you for your comment. The addition of drainage and ablation was made because the evidence showed there was no difference in the rates of spontaneous pregnancy between this intervention and cystectomy while having a beneficial effect on ovarian reserve, and so it provides another treatment option. As the recommendations state, the decision of which surgical option is used should take considerations of ovarian reserve into account, but the choice from



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			Anecdotal evidence suggests that this latter approach tends to reduce pain and other symptoms in more patients than ablation alone. In turn, this would tend to indicate fewer operations / interventions needed subsequently, although lack of appropriate clinical coding can make it more challenging to quantify. Observational studies suggest that recurrence rates are significantly lower following cystectomy rather than ablation. Furthermore, for those fertility patients taking Clomid or similar, excision of all disease (including endometrioma) prior to commencing fertility treatment is desirable if patients are not to experience an intolerable level of pain / symptom recurrence. Conversations with our members indicate that, whilst fertility can be a priority for many of them and should be managed as such, they also need to be confident that pain and other symptoms associated with endometriosis, including organ dysfunction, will be treated optimally at the same time for the sake of wider wellbeing and quality of life. We are not sure that the recommendation in its current form adequately reflects this.	these 2 options would be an individualised decision, If the woman or person prefers complete excision for optimal symptom relief, even if that may impact ovarian reserve, that would be a valid choice. Egg quality was not an outcome of interest listed in the predefined protocol as the committee agreed that surgery would not have any impact (good or bad) on eqq quality, and therefore no evidence was reviewed for this.



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			We also query the apparent prioritisation of ovarian reserve (quantity) over egg quality, where the latter might be better preserved following cystectomy rather than drainage, leading to improved pregnancy outcomes.	
FTWW: Fair Treatment for the Women of Wales	Table	3	Whilst we appreciate that this section of the guidance pertains to management of endometriosis where fertility is a priority, and the possible impact of laparoscopic surgery on ovarian reserve, we would still urge the recommendations to include quality of life considerations as part of discussions about benefits and risks. We would also ask that egg quality be considered equitably to ovarian reserve.	Thank you for your comment. This section of the guideline aims to provide advice on interventions that will (or will not) improve the chance of achieving a spontaneous pregnancy, so although quality of life is always an important consideration when making any decisions about treatment options, it was not included in the evidence review as an outcome and so is not listed here as a specific factor to discuss. Egg quality was not an outcome of interest listed in the predefined protocol as the committee agreed that surgery would not have any impact (good or bad) on egg quality, and therefore no evidence was reviewed for this.
International Derp Endometriosis Analysis (IDEA) group	General		We approve the endometriosis fertility statement.	Thank you for your comment.



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Royal College of Obstetricians and Gynaecologists	Table	3	I think this should be applied to women/people who may also be planning/hoping to be able to conceive, not only actively TTC. In providing support to people through Endometriosis UK, I hear from many who are anxious about the likely impact in the future even though they may not be immediately wanting to have a child. Fertility may not yet be a 'problem' but is an issue at the forefront once they have a diagnosis.	Thank you for your comment. The population of women and people included in this review was women or people with endometriosis with subfertility or desiring pregnancy, and the aim was to identify interventions that improved spontaneous pregnancy rates, but outcomes also included less immediate measures such as ovarian reserve. It is therefore hoped that the recommendations will provide advice to people who think they may wish to achieve pregnancy at some point in the future and what the optimal interventions may be for them to maximize their fertility. In addition, the section of the guideline on treatment of endometriosis also provides some advice on taking future fertility into account when planning treatment, even if spontaneous pregnancy is not the main aim of treatment.
University Hospitals Bristol and Weston NHS Foundation Trust	Table		We would have liked to have seen comment on surgery as an adjunct to assisted conception e.g. treatment of hydro/haematosalpinx, drainage of endometriomas +/- GnRH analogues prior to stimulation/egg collection, adhesiolysis to improve/enable access to ovaries for transvaginal egg collection	Thank you for your comment. Use of surgery as an adjunct to assisted conception was not identified as a priority area by NICE surveillance and was therefore outside the scope for this update. Consequently no evidence was reviewed relating to this scenario and no recommendations have been made on this topic.



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University Hospitals Bristol and Weston NHS Foundation Trust	Table		We would have liked to have seen comment on commonly used ovarian reserve sparing techniques e.g. "two stage" procedure (+/- GnRH analogues) with drainage followed by cystectomy	Thank you for your comment. All available evidence which matched the protocol for this review was included, and the evidence review did include some combinations of surgical procedures (for example drainage and ablation), but no evidence was found for drainage followed by cystectomy. The committee made a research recommendation relating to combinations of hormonal and surgical treatment as they agreed this was where there was most uncertainty but did not prioritise a research recommendation relating to two stage procedures.
University Hospitals Bristol and Weston NHS Foundation Trust	Table	1.11.1	We would like to have seen suggestion of at least considering use of the Endometriosis Fertility Index. There is quite robust data regarding using this to predict chances of spontaneous pregnancy following surgery (and a growing body using it with pre-op imaging), which are very helpful counselling patients with decision making. We note that a good recent systematic review paper (Vesali et al 2020) is referenced in the evidence review, which states in its conclusion 'The current findings highlighted the good performance of the EFI score in predicting the	Thank you for your comment. Use of the Endometriosis Fertility Index (EFI) was outside the scope for this update which was focused on interventions to treat endometriosis and not tools to predict chances of pregnancy. The systematic review you have mentioned was not included as it evaluated the accuracy of the EFI as a prediction tool rather than the effectiveness of an intervention. No evidence was therefore reviewed and no recommendations have been made on this topic.



Consultation on draft guideline - Stakeholder comments table 08 February – 22 February 2024

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			non-ART pregnancy rate. However, these findings should be considered with caution because of the substantial heterogeneity between studies.'	
			We think this SR caveat thus warrants a 'consider use' rather than a more definitive 'use' statement in this guideline update. Not referring to its use at all appears perverse given its growing use in practice.	
University Hospitals of Leicester NHS Trust	General		Much needed update, thank you.	Thank you for your comment
University Hospitals of Leicester NHS Trust	Table	1.11.2	Laparoscopic ovarian cyst ablation/drainage – please is it possible to specify (based on the studies) regarding potential methods that can be used for ablation i.e laser or diathermy as there is a risk of damage to the ovary and egg reserve if incorrectly used.	Thank you for your comment. The included studies used a variety of methods for ablation, there were no studies comparing one method of ablation with another, and the level of methodological detail provided was limited so the committee agreed that they did not have sufficient evidence to specify that one method of ablation should be used in preference to another.
University Hospitals of	Table	1.11.4	'Do not offer hormonal treatment in combination with surgery to women or people with endometriosis who are trying to conceive' is a	Thank you for your comment. The purpose of this section of the guideline is to provide advice on treatments that will (or will not) improve the chances



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Leicester NHS Trust			strong statement as there are significant number of women/people with fertility problem who have 8-10 cm (large) endometrioma's along with peritoneal disease and trying to conceive- for these women and people, sometimes it is beneficial to add hormonal treatment post-surgery for a couple of months. Perhaps the recommendation can be considered as – 'Do not <i>routinely</i> offer hormonal treatment <i>unless clinically indicated</i> , in combination with surgery to women or people with endometriosis who are trying to conceive	of spontaneous pregnancy. The evidence for increased rates of live birth and clinical pregnancy when hormonal treatment was used in combination with surgery was limited so the committee agreed that this recommendation should not be changed, and it states that this is because hormonal treatment 'does not improve spontaneous pregnancy rates' (in fact the use of hormones will actually prevent pregnancy). The committee agreed there may be other clinical circumstances where hormones are beneficial – for example to reduce symptoms or improve pain – and these are already covered in the earlier sections of the guideline.