

**Reviewer comments form**

**Guideline: Management of women with endometriosis**

*Review period: 15/02/2013 – 01/04/2013*

Guideline reviewer personal details

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Organisation (if applicable)	De Montfort University, Birmingham City University and University of Nottingham. This review is based on findings from a qualitative interview study, entitled the Endopart study, funded by the Economic and Social Research Council (ES/J003662/1). In-depth interviews were conducted with 22 women with endometriosis and, separately, with their male partners. Further information is provided at <a href="http://www.endopart.co.uk">www.endopart.co.uk</a> .



## Comments to the guideline

Chapter, Section	Page, Line	Comment
Throughout guidance	Throughout guidance	<p>The guidance appears to lack reference to patients' partners, and to how healthcare might be more inclusive of partners and of the couple unit. All chronic illnesses are likely to affect patients' partners to some extent. However, given the absence of an obvious cause or cure, the likelihood of chronic, recurring symptoms, and the potential impact on both sex and fertility, the effect on partners and on the couple unit are especially pronounced. Evidence from the Endopart study (<a href="http://www.endopart.co.uk">www.endopart.co.uk</a>, publications forthcoming) suggests that endometriosis can have a significant impact not only on women but on their partners, and can cause significant distress and strain for the couple unit. Therefore, we recommend that the guidance takes a more couple-focused approach throughout, and advises healthcare practitioners to: recognise the potential impact of endometriosis on not only female patients but on those around them especially partners; recognise the support partners may provide to patients; recognise the insights partners might be able to provide into patients' experiences of endometriosis (e.g. regarding symptoms, treatment efficacy, treatment side effects, etc.); and to therefore be more inclusive of partners.</p>
1. Diagnosis of endometriosis	p. 29-44	<p>The Endopart study suggests that patients receive insufficient information at the point of diagnosis and as such we recommend that healthcare practitioners</p>

		signpost ALL patients towards the national charity Endometriosis UK.
2. Treatment of endometriosis-associated pain	p. 45-73	The Endopart study suggests that patients require more and better realistic information about various aspects of treatment, including detail on procedures, and on the potential effectiveness and side effects of both medical and surgical treatment. In particular, the Endopart study suggests that patients and their partners require honest and realistic information about the likely efficacy and side effects of hysterectomy, to avoid assumptions that this will alleviate all symptoms permanently; and about the recovery process and period following all forms of surgery, to enable better understanding of and planning for the impact this may have on everyday life. Information must be informed by a multidisciplinary perspective. We propose that the guidance could make reference to these suggestions.
3. Treatment of endometriosis-associated infertility	p. 75-82	The Endopart study suggests that women and their partners may experience considerable uncertainty and anxiety regarding the potential impact of endometriosis on fertility, and that decision making regarding planning for and having children can be significantly affected, whether or not women have been diagnosed as infertile and/or are seeking infertility treatment. Information provided by healthcare practitioners can have a significant impact on concerns and on decision making. Therefore, healthcare practitioners need to recognise the uncertainty and anxiety that may be experienced by patients and their partners, and provide patients and partners with information and advice that is based on

		their specific staging and circumstances, as opposed to general or speculative information.
Throughout guidance	Throughout guidance	Considerable guidance is offered relating to endometriosis-associated pain and endometriosis associated- infertility. However, other symptoms, such as fatigue, heavy menstrual bleeding and bowel and bladder irregularities appear to be neglected. The Endopart study and other research (e.g. Jones et al., 2004; Gao et al., 2006) suggests that these symptoms can have a significant impact on quality of life, and as such we propose they are considered more fully within this guideline.
Throughout guidance	Throughout guidance	Linked to the above point, the Endopart study suggests that a number of factors, not only dyspareunia, impact on sex and intimacy for couples, but that couples may not raise such impacts in clinical encounters. We recommend that the guideline advises healthcare practitioners to initiate discussions about the impact of endometriosis on sex, being mindful that factors other than dyspareunia may have an impact, and to facilitate access to specialist support where necessary (e.g. psycho-sexual or relationship counselling).
Appendix 4: Research recommendations	109	The guideline could make reference to recommendations relating to the use of patient-centred interventions. We understand this absence reflects the lack of published reviews of such interventions. However, the guideline also draws attention to the considerable impact of endometriosis on quality of life (e.g. page 5), and the Endopart study and other research suggests that patients report variable, and often negative,

		<p>experiences with healthcare professionals (e.g. Jones et al., 2004) and limited effectiveness of treatment (e.g. Denny, 2004; Jones et al., 2004; Denny, 2009). Therefore, we suggest that the research recommendations should highlight the need for the development and testing of patient-centred self-management interventions, with a psycho-social element and a multidisciplinary approach, to enable women with endometriosis to more effectively manage the condition and the impact it has upon their daily lives.</p>
<p>Appendix 4: Research recommendations</p>	<p>109</p>	<p>Furthermore, the guidance lacks recommendations relating to the use of couple-centred interventions throughout. As stated above, evidence from the Endopart study shows that endometriosis can have a significant impact not only on women but on their partners, and can cause significant distress and strain for the couple unit. Therefore, we suggest that the research recommendations should also highlight the need for the development and testing of couple-centred interventions, with a psycho-social element and a multidisciplinary approach.</p>
		<p>References</p> <p>Denny E. Women's experience of endometriosis. J Adv Nurs 2004;6;641-8.</p> <p>Denny E. 'I never know from one day to another how I will feel': pain and uncertainty in women with endometriosis. Qual Health Res 2009;7;985-95.</p> <p>Gao X, Yeh Y, Outley J, Simon J, Botteman M,</p>

		<p>Spalding J. Health-related quality of life burden of women with endometriosis: a literature review. <i>Curr Med Res Opin</i> 2006;9;1787-1797.</p> <p>Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. <i>J Psychosom Obst Gyn</i> 2004;2;123-33.</p>

## Top 5 of recommendations with priority for implementation

*(not mandatory)*

Based on the recommendations with highest priority for implementation, we aim to develop tools for implementation (e.g. option grids, flow charts, decision aids), in addition to a patient version and a tool for online consultation of the guideline.

Recommendations with priority for implementation could be

- Recommendations that divert strongly from clinical practice
- Recommendations with barriers for implementation: (e.g. availability or costs of an intervention, reimbursement, laws and regulations, unclear formulation of a recommendation needing rephrasing,..)

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