Endometriosis is a chronic gynaecological condition affecting women of reproductive age with an estimated incidence of 5–15%. Symptoms include severe dysmenorrhoea, chronic pelvic pain, fatigue, heavy menstrual bleeding and dyspareunia. It is associated with 40% of attendances at infertility clinics.

Endopart, funded by the UK Economic and Social Research Council (ref:ES/J003662/1), is a qualitative cross-sectional interview study designed to explore the impact of endometriosis on heterosexual couples and to contribute to enhancing the well-being of people living with endometriosis by providing an evidence base for improving couple support.

Methods
Contextual interviews with key informants (n=11) were followed by qualitative interviews with 22 heterosexual couples. Separate, in-depth, face-to-face interviews (n=44) were conducted with women and men. Inclusion criteria for couples were a laparoscopic diagnosis of endometriosis and that couples were living together at the time of interview. Principles of systematic sampling were employed to ensure diversity amongst participants regarding age, ethnicity, illness trajectory, and recruitment route. Interviews were fully transcribed and entered into NVivo for analysis. Data were analysed using a systematic, thematic method, informed by an interpretivist relational approach. Interim outcomes from the study were discussed at an expert stakeholder workshop in order to enhance interpretive validity. Ethical approval was received from De Montfort University and from East Midlands Leicester NHS Local Research Ethics Committee.

Results and discussion
In heterosexual couples, the impact of endometriosis is not confined to women, but has significant implications for the male partner and for the couple’s relationship. The practical and emotional impact on men was found to be substantial. Couples experienced considerable disruption, loss and anxiety across several life domains.

• **Managing daily life** - Women’s working lives were significantly affected, as were couples’ social lives. Endometriosis appeared to have an impact on women’s abilities to undertake household related tasks, resulting in an increased workload for male partners. A minority of couples reported that endometriosis had an all-encompassing negative impact on managing daily life.

• **Sex and intimacy** - The sexual relationships of all couples had been affected by endometriosis, although the nature and extent of this varied considerably. Dyspareunia (pain during sex), bleeding during and/or after sex, fatigue, heavy menstrual bleeding, feeling unwell generally and loss of libido as a result of medication were common factors affecting couples’ sexual relationships. Several couples reported a loss of intimacy, closeness and affection.

• **Planning for and having children** - For 18 of 22 couples, endometriosis had affected their plans to have children. While only half of these had sought and/or received medical fertility treatment or investigations, all 18 discussed a range of impacts including anxiety about ‘anticipated infertility’, impacts on decision making and feelings of loss. Some couples had to make a difficult choice between pain reduction treatment and achieving pregnancy.

• **Communicating and supporting each other** - There was considerable variation in how effectively partners appeared to communicate with each other, and overall couples were more likely to discuss treatment and healthcare and less likely to discuss their feelings about the experience of endometriosis. Many men provided considerable emotional support to their partners, but some strategies, such as ‘being positive’, were not always perceived as helpful by women. A small number of men reported not knowing how to provide emotional support.

• **Mood and tensions** - Endometriosis symptoms and/or treatment impacted significantly on women’s mood, resulting in feelings of depression, tearfulness and/or irritability. In some cases, this caused tensions in couple units, as both partners struggled to cope with the impact on their relationship.

• **Accessing and negotiating healthcare** - There was variability in the level of satisfaction with healthcare reported by couples. Many men were actively involved in their partner’s healthcare, and most women appeared satisfied with their partners’ levels of involvement. Some men took on assertive roles in consultations in their quest for effective treatment. Many couples reported receiving insufficient information from healthcare practitioners about endometriosis, its treatment and management, and having little opportunity to discuss the impact of endometriosis on their relationship.

• **Utilising information and external support** - Women were more likely to seek informal support (e.g. friends and family) and formal support (e.g. support groups and forums) than men. Overall participants suggested that more support and information, tailored to male partners and couples, would be valuable.

Conclusion
Our data demonstrate that endometriosis and its management significantly disrupts the lives of both women and men in many domains. Discussions of management have until now been focused on the woman, largely ignoring the impact on couples. These findings have implications for the development of couple-centred management and counselling, adding unique data to the knowledge base of clinicians and others providing support to people living with endometriosis. Healthcare providers and support groups need to give further attention to the specific needs of men and of couples in the management of this common, chronic condition.