The study

• Endometriosis is a chronic gynaecological condition affecting women of reproductive age. Symptoms include severe dysmenorrhea, chronic pelvic pain, fatigue, heavy menstrual bleeding, and dyspareunia (pain during sex). It is associated with 40% of attendances at infertility clinics. While there is evidence of a negative socio-psychological impact on women, little is known about how couples experience living with endometriosis, and about the impact on male partners. Endopart, funded by the UK ESRC (ref:ES/J003662/1), is a qualitative cross-sectional interview study designed to explore the impact of endometriosis on heterosexual couples.

• A literature review on the social and psychological impact of endometriosis on women’s lives was undertaken and is due to be published in Human Reproduction Update shortly. 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. 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.

Preliminary findings

• Couples experienced considerable disruption and loss across several life domains, although the extent of this varied between couples. Living with endometriosis was also said to strengthen relationships for some couples.

• Symptoms, especially pain, had significant impacts on everyday life (including managing the home, paid work and social lives) for both women and men.

• Planning for and having children was a significant issue for many couples, not only those diagnosed as infertile and/or seeking fertility treatment.

• For all couples endometriosis impacted on sex and intimacy in a number of ways (including the symptom of pain during sex), although the extent of this impact varied.

• Both men and women engaged in strategies to support their partners and to minimise the impact of endometriosis, with varying levels of success. Many men reported taking on additional roles; some provided considerable emotional support, whereas others were unsure how to do this.

• Couples communicated with each other more often and more effectively about issues such as healthcare and treatment than they did about their feelings about endometriosis and its impact on their relationship.

• Women experienced delays to diagnosis and couples’ experiences with healthcare practitioners varied considerably. Many men took on assertive roles in their pursuit of treatment.

• The impact of endometriosis on women, on men and on relationships varied but in some cases was profound. Participants suggested that more support aimed at helping couples would be valuable. In particular, men appeared to be marginalised in endometriosis care and support.

More detailed findings will be made available later in 2013.