



Pro Forma – Informed Choice Endometriosis

1. Your name and the reason for your interest in this inquiry (optional)

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Over recent years the Reproduction Research Group at De Montfort University, Leicester, has undertaken a programme of research, and corresponding development activity, focussed on endometriosis. This includes:

- ENDOCUL – a study into the ways in which minority ethnic women experience endometriosis and its treatment (<http://www.bcu.ac.uk/research/-centres-of-excellence/centre-for-health-and-social-care-research/research-clusters/health-understanding-for-all/endocul>); outputs from the study include:
 - Denny et al. (2010) Endometriosis and cultural diversity: improving services for minority ethnic women, Birmingham City University: Birmingham.
- ENDOPART – a study into the impact of endometriosis on heterosexual couples (www.dmu.ac.uk/endopart); outputs from the study include:
 - Culley et al. (2013a) The social and psychological impact of endometriosis on women's lives: a critical narrative review, Human Reproduction Update, 19, 6, 625-639. (see <https://academic.oup.com/humupd/article/19/6/625/839568/The-social-and-psychological-impact-of>)
 - Culley et al. (2013b) Endometriosis: improving the wellbeing of couples: summary report and recommendations, De Montfort University: Leicester (see www.dmu.ac.uk/endopartreport)
 - Hudson et al (2016) 'We needed to change the mission statement of the marriage': biographical disruptions, appraisals and revisions amongst couples living with endometriosis, Sociology of Health and Illness, 38, 5, 721–735 (see <http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12392/pdf>)
- ENDOPART2 – a project to improve couple support (<http://www.dmu.ac.uk/research/research-faculties-and-institutes/health-and-life-sciences/reproduction-research-group/endopart2-developing-a-knowledge-exchange-partnership-and-improving-support-in-endometriosis.aspx>)
- Survey of the Role of Endometriosis Clinical Nurse Specialists (CNSs) in British Society for Gynaecological Endoscopy (BSGE) Registered Centres

The response below is based on the above work, and therefore based on evidence as opposed to opinion, and is referenced accordingly.

2. Would you be happy for the group to use any comments you make in response to the questions below?

Yes. Please acknowledge the authors of the reports/comments where relevant. Thank you.

3. In your experience, what information is offered to patients who suffer from endometriosis regarding treatment options available?

Our literature review suggests that women report receive insufficient information at diagnosis, and express a desire for more information about surgery (e.g. anaesthetic procedures, the location and size of incisions, possible complications and recovery time and pain) (Cox et al., 2003, in Culley et al., 2013a) and general information about living with and managing endometriosis (Huntington and Gilmour, 2005, in Culley et al., 2013a). Endometriosis is a disease characterised by uncertainty (Lemaire, 2004; Butt and Chesla, 2007; Whelan, 2007; Denny, 2009, in Culley et al., 2013a); this

relates to diagnostic delays (see below) but also to the uncertainty women feel about how to proceed with treatment and about how endometriosis will affect them and will be managed throughout their future lives (Culley et al., 2013a). In the ENDOPART study many couples reported they did not receive enough information from healthcare practitioners about endometriosis or its treatment and management and did not have sufficient opportunity to discuss their condition and in particular its impact on their relationship (Culley et al., 2013b). As one woman stated:

This is in a nutshell what is so frustrating about my disease, all the conflicting messages I am receiving, and trying to seek the best possible treatment and dealing with various GPs all the time, just to make me feel like I am always going back to square one. Why can't I go straight to a designated specialist or walk-in clinic? I have a chronic disease that GPs are clearly not knowledgeable about. I am just so frustrated that I do not have access to someone who is able to treat all the aspects of the disease. (Female participant, ENDOPART study)

Consequently we argue that more information (both verbal and written) about the management, including non-medical- and self-management, of endometriosis should therefore be made available to women, and must be delivered in a helpful format and provided in a timely manner (Culley et al., 2013a).

In addition, women and couples do not appear to receive sufficient information about fertility and endometriosis. Our literature review suggests that women experience uncertainty regarding fertility in the future (Denny, 2009, in Culley et al., 2013a) and report wanting more information about potential infertility (Cox et al., 2003a, in Culley et al., 2013a). Within the ENDOPART study, a small proportion of couples received contradictory advice from endometriosis consultants and fertility consultants, or reported that their fertility treatment was not considered in relation to their endometriosis (Culley et al., 2013b).

The ENDOCUL study also highlighted a lack of information available in alternative languages and tailored to different ethnic and cultural groups. Most of the women in this study were competent English speakers, but several expressed concern at the lack of adequate communication support for those with lower proficiency in English, and many commented on the failure of consultants to fully explain procedures in easy to understand terminology (Denny et al., 2010). The ENDOCUL study produced DVDs and leaflets in 5 languages, as well as a resource for healthcare professionals.

It also appears that information on non-medical and self-management approaches are limited: our literature review suggests that in response to the limitations of medical treatment, some women also attempt to manage their endometriosis and alleviate symptoms through lifestyle changes (e.g. changes to diet and exercise) and through complementary and/or alternative therapies (Cox et al., 2003c; Huntington and Gilmour, 2005; Gilmour et al., 2008; Markovic et al., 2008, in Culley et al., 2013a). However, healthcare practitioners' information and advice giving regarding non-medical and self-management strategies has been described as lacking (Huntington and Gilmour, 2005; Gilmour et al., 2008, in Culley et al., 2013a).

With regard to information provision, it is worth highlighting the important role that support groups play: support/information groups are of value and help women to interpret their experiences, feelings and emotions (in Culley et al., 2013a). Information and confidence gained from such groups allows women to evaluate medical information and negotiate with healthcare practitioners, insurers and employers (Whelan, 2007, in Culley et al., 2013a). Such groups also offer a route into wider patient communities, which are an important source of support. Indeed, women have deemed other

women with endometriosis to be the most useful and valued source of information (Whitney, 1998, in Culley et al., 2013a). The rise in online communication has also provided women with new and different ways to share information and provide and receive support (Emad, 2006; Neal and McKenzie, 2011, in Culley et al., 2013a). Support groups also provide researchers with links to patients for research studies and are an invaluable mechanism to achieve patient and public engagement in research and service improvement activities (Culley et al., 2013a).

4. In your opinion, what barriers exist to diagnosing patients who suffer endometriosis?

As has been frequently documented and evidenced, women experience considerable delays between the start of symptoms and the diagnosis of endometriosis, and many are mis-diagnosed during this time. Within the ENDOPART study, the delays amongst our sample were between six months and 28 years, and the average was 9.1 years (Culley et al., 2013b). Some reported being misdiagnosed with irritable bowel syndrome, appendicitis or an infection. Many women spoke of the difficulties and distress they experienced in trying to get healthcare practitioners to investigate their symptoms. As one woman stated:

It was a really, really stressful time before my diagnosis actually ... the whole burden of trying to figure it out on my own because I didn't feel I was getting enough help from the doctors. I think they should have suspected this sooner. (Female participant, ENDOPART study)

Our literature review suggests that delays to diagnosis occur at both the patient level and the medical level (Ballard et al., 2006, in Culley et al., 2013a):

➤ Diagnostic delay: factors at the patient level

The delay at the patient level refers to the time between symptom onset and seeking medical help. It is suggested that women fail to seek medical help due to difficulty in distinguishing between normal and pathological symptoms; because they consider themselves 'unlucky' as opposed to 'unwell' and because they fear that disclosure would result in embarrassment and in them being perceived as weak (Cox et al., 2003b; Ballard et al., 2006, in Culley et al., 2013a). Women themselves and those around them (family and friends) are frequently unaware of endometriosis as a condition (Denny, 2009; Fourquet et al., 2010, in Culley et al., 2013a). The perception of menstrual irregularities as 'normal' and the perception of menstrual pain as something to be endured also contribute to delay in seeking help (Cox et al., 2003b; Denny, 2004b; Ballard et al., 2006, in Culley et al., 2013a), particularly for adolescents (Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a). Denny (2004b) and Seear (2009a) refer to an 'etiquette of menstruation' (Laws, 1990) whereby in many societies, menstruation itself is perceived as something private and something to be hidden (in Culley et al., 2013a). Women may thus actively conceal their menstrual irregularities, especially from men. Others, such as mothers and friends, facilitate and encourage this concealment (Seear, 2009a, in Culley et al., 2013a). However, the influence of family and friends who are able to identify pain experiences as abnormal and encourage help seeking, as well as disrupted social roles such as in performing education or work tasks, may also serve as catalysts that shift a woman's understanding of her symptoms from being normal to pathological (Manderson et al., 2008, in Culley et al., 2013a). The ENDOCUL study also suggests that women may delay help seeking: participants thought that women would tend to normalise severe period pain, and thought that fertility problems rather than pelvic pain would be the most likely reason for seeking professional help (Denny et al., 2010). The study also highlighted that willingness to discuss topics such as menstruation and dyspareunia, and attitudes towards privacy, confidentiality and being examined by male health professionals, varies across different ethnic groups; for example Greek women were more open to discussing such topics, whereas Chinese women valued privacy and confidentiality more highly and were more circumspect about discussing such topics (Denny et al., 2010). In addition, within ethnic minority communities

there is a limited awareness of endometriosis (Denny et al., 2010).

➤ Diagnostic delay: factors relating to the medical profession

Delays to diagnosis have also been identified once women have sought medical help for their symptoms and misdiagnosis is common (Denny, 2004b; Jones et al., 2004; Huntington and Gilmour, 2005; Denny and Mann, 2008, in Culley et al., 2013a). Studies demonstrate medical level delays, between help seeking and diagnosis, of between 3.7 (Cox et al., 2003a, in Culley et al., 2013a) and 5.7 years (Denny and Mann, 2008, in Culley et al., 2013a). Delays were found to be common at the primary care level and reflect resistance to referral (Denny and Mann, 2008; Nnoaham et al., 2011, in Culley et al., 2013a). Several papers suggest that prior to diagnosis, women commonly experience repeated visits to doctors where symptoms are normalized, dismissed and/or trivialized, resulting in women feeling ignored and disbelieved (Cox et al., 2003a, b; Denny, 2004a, b, 2009; Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a). Women were often initially referred to inappropriate secondary care, or were misdiagnosed, most commonly with irritable bowel syndrome or pelvic inflammatory disease (Jones et al., 2004; Ballard et al., 2006; Denny and Mann, 2008, in Culley et al., 2013a). General practitioners were reported as lacking knowledge, awareness and sympathy and displaying attitudes that perpetuate myths about endometriosis (Cox et al., 2003b; Denny, 2004b; Jones et al., 2004; Denny and Mann, 2008, in Culley et al., 2013a). The ENDOCUL study, which included interviews with healthcare practitioners, reinforces the view that GPs require more information about endometriosis to assist in timely referral and diagnosis (Denny et al., 2010).

5. In your opinion, what barriers exist to treating and/or managing patients effectively who suffer from endometriosis?

Finding a long term, acceptable approach to managing and minimising endometriosis symptoms appears to be a constant battle which causes significant frustration for women and also for those around them, e.g. partners (Culley et al., 2013b). As such, identifying and addressing barriers to effective treatment and management is of paramount importance.

The nature of endometriosis treatment also comprises a barrier to effective management of the condition. Research suggests women typically receive several forms of treatment (Culley et al, 2013b) and there is huge variation in how effective these are (De Graaff *et al.*, 2013, in Culley et al., 2013b). Women in the ENDOPART study reported that whilst some treatments were reported to be very effective, at least for a period of time, women encountered significant difficulties and frustrations when treatments were ineffective, only effective (or advised to be taken) in the short term, and/or caused side effects (either straight away or after a certain time period). Subsequently, many had a 'trial and error' approach to medical treatments, and changed their treatments on a regular basis. Women described a vast range of treatment side effects they experienced including constipation, hot flushes, aches, insomnia, weight gain, pains, fatigue, poor concentration, loss of libido and impact on mood. These side effects had a considerable impact on quality of life, for both women and their male partners, and some found it difficult to disentangle the impacts of the endometriosis and the impacts of treatment side effects (in Culley et al., 2013b).

Relatedly, the link between fertility and many forms of endometriosis treatment appears to be a considerable barrier to the effective management/treatment of the condition: endometriosis treatments often act as a contraceptive or may create risks to fertility. Some couples in the ENDOPART study, therefore, were faced with a difficult choice. Accepting treatment would bring much needed relief from debilitating pain but would mean delaying any attempt to conceive or in the case of hysterectomy, foregoing a pregnancy. However, rejecting treatment because of a desire for children meant sometimes having to live with extreme pain. The decision-making process surrounding this issue was further complicated when partners had different priorities in this regard

(Culley et al., 2013b).

Barriers also appear to be culturally and ethnically diverse, and it would be misguided to advance care taking an 'ethnocentric' approach, based on the assumption that all groups experience similar barriers and that the experiences of White British communities apply to all groups. For example, in the ENDOCUL study, Pakistani women expressed concern about the potential impact of extensive internal examinations on proof of virginity (essential to marriage) and concern that if a woman had treatment with oral contraception (a common treatment for endometriosis) this might be interpreted as her being sexually active, which would also compromise marriage prospects. Chinese women valued privacy very highly, were more circumspect about discussing any personal issues with health professionals and placed great importance on confidentiality. Some women reported that negative interactions with individual healthcare providers were related to cultural insensitivity or misunderstandings (Denny et al., 2010).

Further to this, interviews with health professionals indicated varying degrees of knowledge and concern about the impact of ethnic identity on endometriosis. All expressed the view that it was important to treat patients as individuals, rather than focus on ethnicity. Nurses were more likely to acknowledge the potential impact of culture on access to care and experience of care, though this was often done in somewhat stereotypical ways. Consultants explicitly argued that women's concerns were primarily around getting a diagnosis and appropriate treatment to relieve their pain and address any fertility concerns. Healthcare practitioners thought ethnicity was not of major importance, though some ethnic differences were identified, and poor communication with people whose English is not good was seen as a problem (Denny et al. 2010).

Healthcare practitioners' attitudes and approaches can sometimes create barriers to effective treatment and management. Women in both the ENDOCUL and the ENDOPART studies reported both positive and negative experiences of interactions with healthcare practitioners; negative experiences included doctors not believing in the existence or severity of symptoms, doctors having dismissive attitudes, receiving conflicting advice from different professionals, delays in accessing consultations and treatments and a general insensitivity to their symptoms (Denny et al., 2010, Culley et al., 2013b). Some felt that healthcare practitioners only considered the endometriosis symptoms in treatment decisions, and did not take sufficient account of the side effects experienced (see above); for example one woman stated:

I am very frustrated and angry that the side effects of being on this drug are not taken into consideration. This drug has stopped the pain and bleeding, however it has masked a problem with other problems that have equally reduced my quality of life. (Female participant, ENDOPART study)

6. In your experience, is every patient who requires treatment and/or management for endometriosis offered information about the full range of treatment options available?

See response to question 3. However, in addition the ENDOPART study highlighted variance in how consultations are managed and the extent to which patients (or patients and partners) are informed about the range of treatment options available, and have a 'say' in deciding the course of treatment. This study reported that there was variation in how couples negotiated treatment decisions with consultants. Some couples were entirely led by their consultant, and did not question decisions or make their own suggestions. Others felt they had the right to determine their own treatment, based on their own experiences and research. In the case of one couple when their chosen treatment – a hysterectomy – was denied by their consultant, this resulted in them feeling utterly powerless and frustrated (in Culley et al., 2013b).

7. What do you feel needs to happen to ensure patients have access to information on all appropriate treatment options available for treating and/or managing endometriosis?

More information (both verbal and written) about the management, including non-medical- and self-management, of endometriosis should therefore be made available to women, and must be delivered in a helpful and culturally appropriate format and provided in a timely manner (Culley et al., 2013a). Women with lower proficiency in English need to be offered good communication support. Little information is available about treatment in languages other than English.

8. What recommendations would you make to ensure endometriosis pathways best serve patients?

Better awareness of the varied clinical features and manifestations of endometriosis and selection of the most appropriate investigations by healthcare practitioners may reduce delays to diagnosis at the medical level (Huntington and Gilmour, 2005; Ballard et al., 2006; Denny and Mann, 2008, in Culley et al., 2013a). This can only be achieved by improved education of all healthcare professionals who may come into contact with women with endometriosis (in Culley et al., 2013a). Increasing women's awareness of physiology and of endometriosis through education in schools and via support groups may help women to distinguish between menstrual pain and endometriosis and reduce patient delays in seeking help (Cox et al., 2003b; Lemaire, 2004, in Culley et al., 2013a). Seear (2009a), however, warns that strategies to increase awareness of endometriosis and to help women distinguish between normal and abnormal pain need to be grounded in an understanding of why pain is normalized, and of the stigma associated with menstrual irregularities (Culley et al., 2013a).

Health care management post-diagnosis needs to be more holistic (in Culley et al., 2013a). It should be informed by an understanding of the multidimensional impact of endometriosis and underpinned by a biopsychosocial approach that includes emotional support, stress reduction, social support, adaptive coping strategies, psychosexual treatment and a focus on quality of life issues, sex and relationships, pain management and career counselling (Peveler et al., 1996; Huntington and Gilmour, 2005; Lorenc,atto et al., 2006; Butt and Chesla, 2007; Denny and Mann, 2007; Siedentopf et al., 2008; Seear, 2009b; Roth et al., 2011 , in Culley et al., 2013a).

Healthcare practitioners and support groups should ensure that the support and advice offered to minority ethnic patients is culturally and linguistically appropriate (Denny et al., 2010).

More specific recommendations are that:

- The forthcoming NICE guidance on 'Endometriosis: diagnosis and management', and other information provided by NICE about endometriosis, should include a consideration of the evidence on the psychosocial impact of endometriosis on women and those around them, especially their partners. Guidance on how assessment, intervention and management can encompass a focus on these psychosocial aspects of living with the condition should be included (Culley et al., 2013b).
- Relevant professional bodies (RCN, RCOG, RCGP, BFS, BSGE, NICE) should further incorporate information about endometriosis, the associated delays in diagnosis, the problematic approaches to treatment and management, and the psychosocial impact on couples into the training and development of healthcare practitioners (Culley et al., 2013b).
- UK and European guidelines on the management of endometriosis, in particular the RCOG and ESHRE guidelines, should adopt a more couple-focused approach (Culley et al., 2013b).
- Consultations should be inclusive of the impact of endometriosis on quality of life, and on women, partners and the couple relationship (Culley et al., 2013b).
- Healthcare practitioners can also improve women's and couples' experiences by referring

them to specialist services (e.g. pain clinics, psychosexual counselling); by signposting women and couples to support and information organisations such as Endometriosis UK; and by utilising existing resources produced for women, partners and couples (Culley et al., 2013b).

- Following diagnosis, healthcare practitioners should raise the topic of planning for and having children, and open up a discussion that allows women and couples to explore this important issue and to receive evidence-based information, advice and support from appropriately trained individuals (Culley et al., 2013b).

9. Please include any further information you have not been able to cover in the questions above related to the diagnosis and treatment of endometriosis.

Adolescents

We note a particular paucity of research into the impact of endometriosis on adolescents and younger women. While some authors have suggested the experience of endometriosis is qualitatively different for adolescents (Cox et al., 2003a; Manderson et al., 2008; Markovic et al., 2008, in Culley et al., 2013a), for example in relation to the development of friendships and relationships, early experiences of sex and sexual identity, educational achievement and the pursuit of diagnosis (Culley et al., 2013b), there has been little research focusing specifically on the social and psychological impact of endometriosis on adolescents (although there has been some research into the impact of chronic pain on adolescents) (see Forgeron, 2011, in Culley et al., 2013a). Given the potential impact of endometriosis on mental wellbeing, social life and educational achievement during formative years, such research would be of value (Culley et al., 2013a). Qualitative research into the impact of endometriosis or chronic pelvic pain amongst adolescents would improve understanding of this important issue and aid the development of support, information and healthcare for adolescents; it would also help develop pathways for referral to ensure young women are referred to the appropriate services and not dismissed (Culley et al., 2013b).

Sex and intimacy

As noted above, we recommend that health care management post-diagnosis needs to better address the impact of endometriosis on sex and intimacy, and should enable access to psychosexual treatment.

Our literature review demonstrated the considerable impact endometriosis can have on sex and intimacy (Culley et al., 2013a). Studies suggest a substantial impact of endometriosis on the quality of sex life: between 33.5% (Bernuit et al., 2011) and 71% (Fourquet et al., 2011) of women reported that endometriosis negatively affected their sex lives (in Culley et al., 2013a). Specifically, incapacitating pain and dyspareunia were found to have an impact on sex life (Fourquet et al., 2010, in Culley et al., 2013a). Denny and Mann (2007) and Jones et al. (2004) report that the majority of women who experience dyspareunia subsequently avoid or limit sexual intercourse (Culley et al., 2013a). This results in feelings of inadequacy and guilt (Jones et al., 2004, in Culley et al., 2013a). Fagervold et al. (2009) found a correlation between dyspareunia (which 1/3 reported) and negative impacts on relationships (Culley et al., 2013a). Qualitative research found that women were reluctant to discuss dyspareunia with healthcare professionals and that women reported that healthcare professionals did not ask about this (Denny, 2004a, b in Culley et al., 2013a). However, Bernuit et al. (2011) found that nearly half (47%) of women with diagnosed endometriosis who reported that pain affected their quality of life had visited their doctor due to dyspareunia (Culley et al., 2013a). Interventions to enable couples to address the impact of endometriosis on sexual relations are limited and those that are available are reported by couples to be unhelpful (Butt and Chesla, 2007,



in Culley et al., 2013a).

Relatedly, several studies have found that women feel that the symptoms and experience of endometriosis more generally (including but not limited to dyspareunia) have had a negative impact on their relationships and have in some cases contributed to relationship breakdown (Cox et al., 2003c; Denny, 2004a, b; Jones et al., 2004; Huntington and Gilmour, 2005; Fagervold et al., 2009 in Culley et al., 2013a).

Within the ENDOPART study, the sexual relationships of all couples had been affected by endometriosis to a greater or lesser extent (Culley et al., 2013b). Pain during or after sex (dyspareunia) was common but women reported a range of other factors which impacted on intimacy: bleeding during and/or after sex, general fatigue and feeling unwell, reduced sexual desire as a result of medication, having a low mood, the stress of trying to get pregnant and feeling generally unattractive and unfeminine. In nearly half of the couples sex was reported to be non-existent or rare, either at the time of the interview or in a recent phase, and others reported reduced frequency of sex. The absence or infrequency of sex meant that couples did not have opportunities to experience intimacy through sexual relations, and some couples had not found alternative ways of expressing closeness. Dyspareunia meant that some women had to make a difficult choice between avoiding sex, which resulted in them feeling guilt, loss and worry about how this would affect the relationship or enduring painful sex in order to be intimate and close with their partner. Four of the women we interviewed reported that they concealed dyspareunia from their partners, or had done so in the past, in order to minimize the impact of endometriosis on their relationships. Men also spoke at length about the impact of endometriosis on sexual relations with their partners. Most men were aware of the potential for pain, and this fundamentally affected their feelings and behaviour regarding instigating sex. Many men spoke of feeling hesitant and tentative, and were often reluctant to approach their partner. Overall, the study suggests that the impact of endometriosis on sex and intimacy is profound. Very few couples had been given information about the possible impact on sex and intimacy and few had sought or been offered help with the sexual implications of endometriosis or its treatment side-effects (Culley et al., 2013b).

Planning for and having children

Planning for and having children is also an issue that is of considerable importance to many women and couples.

Our literature review evidences mixed evidence regarding the impact of endometriosis on fertility. Sepulcri and do Amaral (2009) and Christian (1993) reported that 50% of couples had experienced problems conceiving (Culley et al., 2013a). Infertility may be more common however as Fourquet et al. (2010) found that 71% of women had attempted to conceive and 90% of these had experienced difficulties (Culley et al., 2013a). However, Fourquet et al. (2010) also found that only 47% of women who had difficulties conceiving sought infertility treatment and Mathias et al. (1996) found that only 4% of women were undergoing infertility treatment (Culley et al., 2013a). Infertility, or concerns about possible infertility, is reported to result in worry, depression and feelings of inadequacy among women, and to contribute to relationship breakdown (Jones et al., 2004 in Culley et al., 2013a). However, other studies found no correlation between infertility and negative effects on relationships (Fagervold et al., 2009, in Culley et al., 2013a). Women felt that GPs' attitudes and knowledge, and their experiences of delayed diagnosis, subsequently influenced their experiences of in/fertility (Denny and Mann, 2008, in Culley et al., 2013a). Women experience uncertainty regarding fertility in the future (Denny, 2009) and report wanting more information about potential infertility (Cox et al.,

2003a) (Culley et al., 2013a).

In the ENDOPART study, 18 out of 22 couples reported that endometriosis had in some way affected their plans to have children (Culley et al., 2013b). The data, therefore, strongly suggest that either actual or *anticipated* infertility was a significant issue for the vast majority of the couples in our study. Couples discussed a range of impacts including effects on decision-making about whether or when to have children and how many. Just half of these couples had sought and/or received medical fertility investigations or treatment. When talking of their fertility problems, women spoke of feelings of loss, grief, distress and upset.

It's a complete nightmare to realise that you're not able to have children and you still have to keep trying. There is this pressure on you to keep trying, you kind of feel that it might not work. It's heart breaking, it's been very hard. So yes, we've had some very low points. It's just yes, very, very stressful. (Female participant, ENDOPART study)

However, even those women who had not, for a variety of reasons, sought advice on fertility issues expressed considerable anxiety about the *possible* impacts of endometriosis on childbearing. These women also spoke of the emotional distress caused by anticipated infertility.

It always comes back to this: my panic to have a child ... the panic is there when really our first year of marriage should be very calm and enjoyable. But for me there's that underlying panic. (Female participant, ENDOPART study)

The biggest concern for me is will I be able to have children? So I'm very emotional about my period and the pain every month. So it's kind of slipped into another dimension now ... I accept it, I'm ok that I've got endometriosis, but now I'm worried about the impact it's going to have. (Female participant, ENDOPART study)

Men also spoke of their emotional experiences in relation to fertility issues. Amongst couples who were receiving or had experienced fertility treatment, men spoke of feelings of disappointment, distress and upset.

Coming to terms with not having children of our own and the whole process of IVF, going through it, is really traumatic and for me that's been the most painful element of the whole process. (Male participant, ENDOPART study)

The impact on partners

A small body of research has explored the impact of endometriosis on partners, and has included partners in data collection activity. Fernandez's small scale study explored the experience of 16 male partners of women with endometriosis and described men's emotional responses as mirroring the Kubler-Ross grieving process, including shock and denial, anger, anxiety, isolation and powerlessness, low mood and also acceptance and relationship growth (Fernandez et al., 2006). These findings were confirmed by a study of 13 couples, reporting disruptions to day to day life and a significant impact on sexuality and intimate relatedness (Butt and Chesla, 2007).

The ENDOPART study was the first UK based qualitative study to explore the impact of endometriosis on both women and their male partners. Findings suggest that endometriosis can affect quality of life of couples in complex and multidimensional ways (Culley et al., 2013b). Several life domains are



affected, including sex and intimacy, planning for and having children, working lives and household income, household activities and social lives, and this impact s on both partners. Endometriosis has a considerable emotional impact: many women reported experiencing feelings of frustration, inadequacy, loss, guilt and powerlessness, while men reported feeling helpless, frustrated, worry and anger. Despite taking on additional support tasks and roles, men are often marginalised in relation to endometriosis: there is little awareness of their feelings and needs, and there is little information and support for male partners. Whilst this is understandable, it is clear that men's experiences and responses are different to those of women, and that men also have unmet needs. In many cases, the overall impact on relationships is profound. In some cases, living with endometriosis has strengthened bonds, and in others it has led to significant strain (Culley et al., 2013b).

Subsequently we argue that endometriosis care and support needs to take a more couple focused approach, inclusive of relationship issues. There is a need for information and support aimed at helping partners and other family members to understand endometriosis and its impacts. This information could usefully help partners and family members to support women with endometriosis effectively, and help partners cope themselves (Culley et al., 2013b). In addition, research into the impact of endometriosis on couples and on partners still constitutes a relatively small body of work, and this warrant further investigation (Culley et al., 2013a).

Ethnicity and culture

It is essential that endometriosis care and management is appropriate for and inclusive of Black and Minority Ethnic groups (Denny et al., 2010). Although the experiences and concerns of women in the ENDOCUL study arise for many women regardless of ethnicity, differences of culture, language and religion are often important to women in gaining a diagnosis and in the experience of living with endometriosis. For all women therefore, it is important that health professionals and those supporting women have a good understanding of the socio-cultural context of people living with endometriosis. Healthcare providers should access training specifically on the way in which ethnicity might impact on endometriosis. Healthcare providers should be encouraged to analyse data by ethnic group and establish any patterns of differential diagnosis, treatment or indeed access to treatment. There is a clear need for interpreting services to be available in NHS Trusts, alongside measures to increase the confidence of users in the effectiveness and confidentiality of services (Denny et al., 2010).

10. Please include any further information you have not been able to cover in the questions above related to the diagnosis and treatment of women's health conditions more generally.

Please contact the secretariat at appgwh@pbpoliticalconsulting.com or call 020 7735 6963 for further information.