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| Pro Forma- Informed Choice Endometriosis | |
| 1. | Your name and the reason for your interest in this inquiry (optional) |
| | <p>Prof Lorraine Culley, Dr Nicky Hudson, Dr Helene Mitchell, Wendy, Caroline Law, De Montfort University</p> <p>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:</p> <ul style="list-style-type: none"> • ENDOCULa 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/endocu); outputs from the study include: <ul style="list-style-type: none"> ¾ Denny et al (2010) Endometriosis and cultural diversity: improving services for minority ethnic women, Birmingham City University: Birmingham. • ENDOPARTa study into the impact of endometriosis on heterosexual couples (www.dmu.ac.uk/endopart); outputs from the study include: <ul style="list-style-type: none"> ¾ Culley et al. (2013a) The social and psychological impact of endometriosis on women's lives: a critical narrative review, Human Reproduction Update, 19, 632-639 (see https://academic.oup.com/humupd/article/19/6/625/839568) ¾ Culley et al. (2013b) Endometriosis: improving the wellbeing of couples: summary report and recommendations, De Montfort University: Leicester (see www.dmu.ac.uk/endopartreport) ¾ 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, 37, 721-735 (see http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12392) • ENDOPART2a project to improve couple support (http://www.489-0237w/c9-0237w-95tiy-se-sl-10.7(ea0in8) <p>Gynaecological Endoscopy (BSR Registered Centres)</p> <p>The response below is based on the above work, and therefore based on evidence as opposed to opinion, and is referenced accordingly.</p> |
| 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? |
| | <p>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) (Ch, 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; De 2009, in Culley et al., 2013a).</p> |



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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, particularly its impact on their relationship (Culley et al., 2013b). As one woman stated:



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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) and McKenzie, 2011, in Culley et al., 2013a). Q2TT4619u.8(t)-2.06(p)-0.5(o)1.8(r)-2.2(t) g.6(r.6(o)-9.6(u).06(p)-



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

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(Culley et al., 2013b)



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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?



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- them to specialist services (e.g. pain clinics, psychosexual counselling); by signposting and couples to support and information organisations such as Endometriosis UK by utilising existing resources produced for women, partners and couples (Ulley et al., 2013b)
- Following diagnosis, healthcare practitioners should raise the topic of planning for and having



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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 shared 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 effects of endometriosis on childbearing. These women also spoke of the emotional distress caused by anticipated in.9()-11.2(an)2.3,b s5.9os-0.0o8(ety)9



affected, including sex and intimacy, planning for and having children, working lives and household income, household activities and social lives, and this impacts 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 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 stress (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 warrants 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 ENDOCUS 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 social and 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 collect 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, 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 question 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.