Institution: De Montfort University

Unit of Assessment: 20

Title of case study: Improving Care, Management and Support for Endometriosis in the UK and Europe

Period when the underpinning research was undertaken: 2012–2013

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Prof. Lorraine Culley	Professor	1990–2013
Prof. Nicky Hudson	Professor	2002–present
Caroline Law	Research Fellow	2012–present
Dr Helene Mitchell	Senior Lecturer	2005–present
Dr Wendy Norton	Associate Professor	1999–present

Period when the claimed impact occurred: 2013–2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Endometriosis is a chronic, gynaecological condition affecting 176,000,000 women worldwide. ESRC-funded research by De Montfort University (DMU) has enhanced management and care of women in the UK and Europe with the condition and improved support for women and their male partners in the UK. The All Party Parliamentary Group on Women's Health, National Institute for Health and Care Excellence (NICE), European Society of Human Reproduction and Embryology (ESHRE), Royal College of Nursing (RCN) and Endometriosis UK have used the research to inform the development of healthcare guidelines and the training of healthcare professionals, and to raise awareness and improve couple support.

2. Underpinning research

Endometriosis affects approximately 10% of women of reproductive age: 176,000,000 women worldwide. Symptoms include pelvic pain, fatigue, heavy and painful periods, pain during sex and subfertility, and the effects can be devastating. Despite its high global prevalence, the lack of a definitive cure and its economic cost, it has remained, until recently, a hidden condition, chronically under-diagnosed and consistently neglected in healthcare and clinical guidelines.

Prior to our ESRC-funded 'ENDOPART' study (GBP91,308.43; 2012–2013), virtually no attention had been paid to the impact of the condition on couples. This study investigated the impact of endometriosis on heterosexual couples, provided an evidence base for improving couple support [R1] and was the first European-based study to include male partners. It was led by the Centre for Reproduction Research, DMU (Prof. L. Culley (PI), Prof. Nicky Hudson, Dr Helene Mitchell), with Co-Investigators from Birmingham City University (Prof. Elaine Denny) and University of Nottingham (Mr Nick Raine-Fenning). It comprised context-setting interviews (n=11) and a literature review [R2]; qualitative interviews with women and their male partners (n=44); and a stakeholder workshop (attended by people with endometriosis and their partners, academics, health professionals, support groups) to discuss findings and consider how support for couples could be improved. This activity enabled the co-production of recommendations for policy, practice and research. The study was overseen by an advisory group engaging end users throughout and providing a catalyst for our sustained impact activities.

The findings confirmed the detrimental effect on women's lives and illustrated the considerable impact on the quality of life of couples [R3, R4, R5]. Overall, the findings demonstrated an urgent need for care and management which acknowledges the emotional, sexual and relational impact of the disease. Study stakeholders welcomed the development of information and support to help cope with its impacts and to manage the relational aspects of living with endometriosis.

Recommendations were made for policy, strategy and professional bodies, healthcare practitioners, and support, information and campaigning organisations, and focused on improving care, support and management. The report and recommendations were disseminated to stakeholders and beneficiaries including NICE, ESHRE, RCN, the British Society for Gynaecological Endoscopy (BSGE: the society for gynaecologists who specialise in endometriosis surgery) and other professional and policy bodies. The report was disseminated via a study website and mailing list (over 250 people and organisations internationally) and a podcast. Endometriosis UK disseminated the report via their website and newsletter (to 25,000 people).

Following the study, we won institutional funding for a knowledge exchange project with Endometriosis UK, ENDOPART2 (2015–2017, GBP5,360, PI Hudson), to enable the charity to use the findings to improve support for women and their male partners. We collaboratively developed and implemented a series of support resources (see Section 4).

Alongside this, we developed additional work to enhance healthcare practice. The ENDONURSE study (2017, DMU funding, GBP2779.60, PI Norton) was designed with the BSGE to evaluate the UK Endometriosis Clinical Nurse Specialist (CNS) role. A survey and interviews were conducted to assess the benefits of this role and provide evidence for future role development [R6].

3. References to the research

R1 comprehensively outlines the main findings from the ESRC-funded study and sets out recommendations co-produced with people with endometriosis and their partners, academics, health professionals and support groups at the study's stakeholder workshop. This widely disseminated report catalysed and underpins the impact activity and additional outputs from the study.

R2 to R6 illustrate the broad dissemination of research findings across disciplines: these were published in ESHRE journals - leading journals within clinical sciences [R2, R4]; a leading sociology journal [R3, R5]; and a practice-focused journal centred on nursing and midwifery practice, research, education and policy [R6]. All were subject to rigorous peer-review processes. R3 was recommended in Faculty Opinions as of special significance in the field by Prof. Lone Hummelshoj, Chief Executive of the World Endometriosis Society and the World Endometriosis Research Foundation, and editor-in-chief of Endometriosis.org, the global forum for news and information in endometriosis (https://facultyopinions.com/prime/726023976). R6 was devised specifically to advance practice generally and Endometriosis CNS role development specifically within BSGE centres.

[R1] Culley, L., Hudson, N., Mitchell, H., Law, C., Denny, E. and Raine-Fenning, N. (2013a) *Endometriosis: Improving the wellbeing of couples: Summary report and recommendations*, Leicester: De Montfort University; https://www.dmu.ac.uk/research/centres-institutes/crr/publications.aspx

[R2] Culley, L., Law, C., Hudson, N., Denny, E., Mitchell, H., Baumgarten, M. and Raine-Fenning, N. (2013b) 'The social and psychological impact of endometriosis on women's lives: a critical narrative review', *Human Reproduction Update*, 19(6): 625–639; https://doi.org/10.1093/humupd/dmt027

[R3] Hudson, N., Culley, L., Law, C., Mitchell, H., Denny, E. and Raine-Fenning, N. (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; https://doi.org/10.1111/1467-9566.12392

[R4] Culley, L., Law, C., Hudson, N., Mitchell, H., Denny, E. and Raine-Fenning, N. (2017) 'A qualitative study of the impact of endometriosis on male partners', *Human Reproduction*, 32(8): 1667–1673; https://doi.org/10.1093/humrep/dex221

[R5] Hudson, N., Law, C., Culley, L., Mitchell, H., Denny, E., Norton, W. and Raine-Fenning, N. (2020) 'Men, chronic illness and health work: Accounts from male partners of women with

endometriosis', *Sociology of Health and Illness*, 42(7): 1532–1547; https://doi.org/10.1111/1467-9566.13144

[R6] Norton, W., Mitchell, H., Holloway, D. and Law, C. (2020) 'The role of Endometriosis Clinical Nurse Specialists in British Society for Gynaecological Endoscopy registered centres: A UK survey of practice', *Nursing Open*, 7(6): 1852–1860; https://doi.org/10.1002/nop2.574

4. Details of the impact

The ESRC research culminated in 2013 with a stakeholder event at DMU, designed to catalyse a range of impacts. These included enhanced management and care of women in the UK and Europe, and improved support for women and their male partners in the UK. Recognition of the condition as one affecting couple relationships has been enhanced within policymaking, and amongst practitioners, charities, women and their partners and the public. Impacts were realised via parliamentary debate, new clinical guidelines, training for and dissemination to professionals, capacity-building for Endometriosis UK, and media coverage.

(1) POLICY CHANGES: IMPROVED CARE

Our evidence about the impact of endometriosis on sex and intimacy was utilised by the All-Party Parliamentary Group on Women's Health (APPGWH) in their report 'Informed Choice? Giving Women Control of Their Healthcare' (2017) [C1]. The APPGWH's work aimed to raise awareness of endometriosis, and to improve experiences of diagnosis, treatment and care. Based on our evidence the report calls for couple-focused care including in the area of sex and intimacy. The report demonstrates our impact on UK parliamentary debate and the public profile of the condition.

> '[Endometriosis] can have significant effects on the emotional well-being of women and their families and many would benefit from being able to discuss issues such as sexual relationships with trained professionals.' [C1: 38]

Our final report was cited as evidence of the impact of endometriosis on couple relationships in the new NICE guideline to inform diagnosis and management (2017) [C2]. The guideline, comprising evidence-based guidance to healthcare professionals in England and Wales, highlighted the impact of endometriosis on relationships, and recommended that partners should be involved in healthcare decisions, and that assessments of support should include women's psychosexual needs. Internationally, our work informed the development of ESHRE guideline on endometriosis (September 2013) [C3] for healthcare professionals in 110 countries. This guideline highlights the significant impact the condition may have on partners and couple relationships. Both NICE and ESHRE utilised our research in their guidelines about the need for professionals to adopt a couple-centred approach to care, ensuring improvements for women and their partners.

> 'Chronic illnesses, like endometriosis, are likely to affect patients' partners to some extent. In endometriosis, the effect of the disease on partners and on the couple unit are especially pronounced given the absence of an obvious cause or cure, the likelihood of chronic, recurring symptoms and the potential impact on both sex and fertility.' [C3: 5–6]
>
> 'If women agree, involve their partner (and/or other family members or people important to them) and include them in discussions.' [C2: 7.8; recommendation 16]

(2) IMPROVED KNOWLEDGE AND SKILLS AMONGST PRACTITIONERS

The skills of UK specialist endometriosis nurses have been improved. Directly emerging from our workshop in 2013, the RCN, the BSGE and Endometriosis UK used our recommendations to collaboratively produce a new knowledge and skills framework for nurses [C4] (4,702 copies distributed) and endometriosis fact sheet [C5] (8,745 copies distributed). Women (and partners) attending NHS specialist endometriosis centres (62 centres in England and Wales) receive improved care due to the framework for nurses in those centres. Additional training and information sessions for nurses were also held by the team and positively evaluated in 2015 (RCN & BSGE), 2018 and 2019 (Royal Surrey County Hospital) [C6].

> ‘This session has given me a greater understanding of how the condition impacts on relationships.’ (Specialist nurse, training session)

Evidence from our research was also disseminated to healthcare practitioners via the RCN annual conference (325 people attended), a course on endometriosis and sex for European practitioners in Belgium (65 people attended), a workshop for practitioners in Italy (35 people attended) and in a UK BSGE centre (attended by 35 healthcare professionals).

> ‘This unique and innovative study provided evidence to demonstrate and raise awareness of the ways in which the condition can affect partners and relationships, and crucially the way healthcare practice can be improved to better support women and their partners’ (Co-Director, EXPPECT Centre for Pelvic Pain and Endometriosis).

(3) CAPACITY-BUILDING FOR ENDOMETRIOSIS UK

The work of the national charity, Endometriosis UK, has been enhanced. Together we developed the first tailored intervention for couples (a face-to-face support session) and trained group leaders to deliver the session in 6 regions. Participants at the support sessions reported having learned new approaches to coping [C7]. We developed accompanying online resources (viewed 110,676 times, 2,085 pdf downloads), and a film about endometriosis (5,626 views) [C8].

> ‘It was reassuring to hear that others have same issues and that communication is vital to helping deal with the effects of endo.’ (Session attendee – person with endometriosis) [C7]
>
> ‘[The session helped with] understanding when she [female partner] is upset.’ (Session attendee – partner of someone with endometriosis) [C7]

(4) PUBLIC AWARENESS-RAISING

The study has brought the topic of endometriosis and in particular the impact of endometriosis on couple relationships and partners into public discourse via high-profile mainstream media outlets (BBC Radio 4 Women’s Hour [C9], Radio 5 Live). It also led to an Endometriosis Awareness Week in 2018 for staff and students at DMU (50 people attended), leading to increased understanding of the condition among attendees. Our work has received international coverage with North American outlets Reuters and ReproJustice, demonstrating sustained public and international awareness-raising.

> ‘The study offers some much-needed insight into endometriosis’ bearing on [women’s] relationships with men.’ (https://www.reprojustice.com/stories/endometriosis-painless-sex-not-a-priority-but-should-it-be)

Key stakeholder organisations have verified the significance of this programme of work, and its impact [C10].

5. Sources to corroborate the impact

[C1] APPGWH final report.
In the uploaded version, our impact is highlighted as follows:

- p 2 DMU acknowledged – acted as reviewer
- Culley et al. cited as evidence on pp 27, 29, 31, 32, 33, 38, 29, references on p 49.

The online version (*without* above highlighting) is available here: http://www.appgwomenshealth.org/inquiry2017

[C2] NICE guideline on endometriosis – final guideline.
In the uploaded version, our impact highlighted is highlighted as follows:

- ENDOPART cited as evidence on pp 66, 67, 73, 73–74, 74, 75, 76, 77, 78, 79–80, 80–81, 82–83, 84, 84–85, 85, reference on p 331
- In response to our stakeholder comments on draft guideline:
    - New recommendation added p 91, 7.8.13
    - Additional detail added to pre-existing recommendation p 91, 7.8.14
    - Additional detail on aspect of living with endometriosis added p 82 (see paragraph starting ‘Data from 1 study…’).

The online version (*without* above highlighting) is available here: https://www.nice.org.uk/guidance/ng73/evidence/full-guideline-pdf-4550371315

[C3] ESHRE guideline on endometriosis – final guideline.
In the uploaded version, our impact is highlighted as follows:

- p 95 Lorraine Culley listed as reviewer
- pp 5–6 additional text added in response to our reviewer comments on draft guideline
- p 88 additional recommendation for future research added in response to our reviewer comments on draft guideline.

The online version (*without* above highlighting) is available here: https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline

[C4] Knowledge and skills framework for Endometriosis Clinical Nurse Specialists – RCN. https://www.rcn.org.uk/professional-development/publications/pub-007239

[C5] RCN endometriosis fact sheet. https://www.rcn.org.uk/professional-development/publications/pub-007240

[C6] Endometriosis Clinical Nurse Specialist evaluation data – responses after training session 2018 and 2019 (available on request).

[C7] Support group member evaluation data – responses after face-to-face support session tailored intervention (available on request).

[C8] Endometriosis and Couples – online resources created by DMU and Endometriosis UK. https://www.endometriosis-uk.org/endometriosis-and-couples

Please note the film is only available in the online version, not the uploaded PDF version which contains text from this resource only.

[C9] BBC Radio 4 Women’s Hour 7 August 2017 with guest Prof. Nicky Hudson. https://genome.ch.bbc.co.uk/explorer/b08zzljw

[C10] Letters of support from key stakeholder organisations.