**Institution:10007140 Birmingham City University**

**Unit of Assessment: 03: Allied Health Professions, Dentistry, Nursing and Pharmacy**

**Title of case study: Effecting Endometriosis Policy and Clinical Guidance, Tackling Menstruation Taboos**

**Period when the underpinning research was undertaken: 2004 – 2018**

**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:** |
|---|---|---|
| Professor Elaine Denny (ED)<br>Dr Annalise Weckesser (AW) | ED – Professor Emeritus<br>AW – Senior Research Fellow | ED 1988-2013<br>AW 2012-present |

**Period when the claimed impact occurred: 2013 – 2020**

**Is this case study continued from a case study submitted in 2014?** No

## 1. Summary of the impact (indicative maximum 100 words)

Birmingham City University's endometriosis research shapes national and international clinical health guidelines and policy. The first-ever (2017) NICE guidance on endometriosis cites, and gives commendation to, BCU research to improve care for the estimated 1.5 million women in the UK with the condition. The (2017) All Party Parliamentary Group Women's Health Inquiry, citing numerous BCU studies, led to new endometriosis training from professional bodies (Royal College for Obstetricians and Gynaecologists and Royal College of General Practitioners) and mandatory menstruation education for 7.25 million pupils in England. BCU research informed wider societal conversations about endometriosis, tackling taboos that surround menstruation.

## 2. Underpinning research (indicative maximum 500 words)

Endometriosis, the growth of endometrial-like tissue outside of the uterus, is the second most common gynaecological condition in the UK. The chronic, incurable condition is commonly associated with severe pelvic pain, painful menstruation, dyspareunia (painful intercourse) and infertility. These symptoms impact an estimated 1 in 10 women of reproductive age living with endometriosis worldwide. Within the UK, patients face an average delay of 8 years for a diagnosis. Menstruation misconceptions exacerbate the hidden nature of the condition.

Since 2004, Birmingham City University (BCU) has conducted eight social research studies, produced 18 peer-reviewed publications and three reports on endometriosis, attracting £2,085,781 in competitive funding from bodies including the National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) (see Underpinning External Grants for details in Section 3). Research most relevant to impacts highlighted in this case study are detailed below.

How endometriosis affects women's everyday lives was not understood before Denny's (2004) study [R01]. R01 was the first study to evidence how the condition affects 'all aspects of a woman's life,' including their psychosocial wellbeing, intimate relationships, and family, work and social lives. The study found women experience prolonged diagnostic delay, despite severe and debilitating pelvic pain, with health practitioners often dismissing such pain as typical menstrual pain. R01 recommended health practitioners investigate women's reported pain more seriously.

Before Denny's 2007 study [R02], how endometriosis-related dyspareunia impacts women's quality-of-life was not known. R02 was the first study to evidence how dyspareunia significantly impacts women's self-esteem and their relationships with partners. Denny's 2009 study [R03] found women with endometriosis experience uncertainty about the condition from diagnosis, through the course of the illness and into the future. As endometriosis is an 'enigmatic disease,' women live with uncertainty about symptom relief and their fertility. R03 evidenced the need for improved patient-practitioner communication, information and support for women to help them manage this uncertainty.

Research [R04] from Endometriosis and Cultural Diversity (Endocul): Improving Services for Minority Ethnic Women, (NIHR's Research for Patient Benefit grant: PB-PG:0906-11145) was the first in the UK to explore how to improve minority ethnic women's experience of endometriosis and its treatment. R04 (2010) found women's specific cultural contexts shape their experiences of endometriosis, especially infertility. The study recommended more culturally sensitive information and support provision for such communities.

Research [R05] from EndoPart: Endometriosis – Improving the Experiences of Couples (UKRI's Economic and Social Research Council grant: ES/J003662/1) was the first UK study to include the male partners of women with endometriosis. R05 (2013) evidenced the significant psychosocial and practical implications of endometriosis for couples. Key study recommendations included the creation of NICE guidance on the management of endometriosis, improved practitioner training on recognising condition symptoms, and increased awareness about the condition generally as well as its effect on partners and on couple relationships [R05: p33- 37].

Denny's and Weckesser's qualitative research [R06] for Preventing Recurrence of Endometriosis by Means of Long Acting Progestogen Therapy (PreEmPT) Trial (NIHR-Health Technology Assessment grant: 11/114/01) was the first published study focused on women's experiences of medical treatments for endometriosis. R06 (2018) found women "feel desperate" and are "willing to try anything" for symptom relief. As in Denny's earlier 2004 study [R01], R06 evidenced how, nearly two decades on, women continue to report dismissal of their pain symptoms and prolonged diagnostic delay.

*BCU research (R01-R06) revealed how endometriosis dramatically shapes every aspect of women's lives and how, for nearly two decades, women continue to face prolonged diagnostic delays and dismissal of their symptoms by healthcare professionals.*

## **3.References to the research** (indicative maximum of six references)

All below publications have been subject to peer review. BCU researchers in bold.

**R01**: **Denny, E.** (2004) Women's experience of endometriosis. Journal of Advanced Nursing. 46 (6): 641-648. *DOI: 10.1111/j.1365-2648.2004.03055.x* (cited 107 times in Scopus)

**R02**: **Denny, E**, Mann, C.H. (2007) Endometriosis-associated dyspareunia: the impact on women's lives. BMJ Sexual & Reproductive Health. 33 (3):189-193. *http://dx.doi.org/10.1783/147118907781004831* (cited 107 times in Scopus)

**R03**: **Denny, E.** (2009) "I never know from one day to another how I will feel" Pain and uncertainty in women with endometriosis. Qualitative Health Research. 19(7):985-995. *https://doi.org/10.1177/1049732309338725* (cited 57 times in Scopus)

**R04: Denny, E.**, Culley, L., Papadopoulos, I., and P. Apenteng. (2010) Endometriosis and cultural diversity: improving services for minority ethnic women. Final Report for the Research for Patient Benefit Grant (PB-BG0906-114). Birmingham City University. *https://cultureandcompassion.com/wp-content/uploads/2015/04/Endometriosis-and-cultural-diversity.pdf*

**R05:** Culley, L., Hudson, N., Mitchell, H., Law, C., **Denny, E.**, and N. Raine-Fenning. (2013) Endometriosis: Improving the wellbeing of couples. Summary report and recommendations. Funded by the UK Economic and Social Research Council. (Project reference: ES/J003662/1)

https://www.dora.dmu.ac.uk/xmlui/bitstream/handle/2086/17477/Endopart%20study%20summary%20report%20and%20recommendations.pdf?sequence=1

**R06: Denny, E., Weckesser, A**., Jones, G., et al. (2018) Women's experiences of medical treatment for endometriosis and its impact on PRE-EMPT trial participation: a qualitative study. Pilot Feasibility Studies. 4, 168. https://doi.org/10.1186/s40814-018-0358-5 (cited 2 times in Scopus)

**Underpinning External Grants:**

- Endometriosis and Cultural Diversity (**Endocul**): Improving Services for Minority Ethnic Women; **NIHR Research for Patient Benefit Programme**, PB-PG:0906-11145, 2008-2010; Grant-holding institution: Birmingham City U; PI: E. **Denny** (Birmingham City U), CI's: L. Culley (DeMontfort U), I. Papadopoulos (Middlesex U); **£252,342**
- Endometriosis: Improving the Wellbeing of Couples (**EndoPart**); **UKRI Economic and Social Research Council**, ES/J003662/1, 2012-2013; Grant holding institution: DeMontfort U; PI: L. Culley, Co-I's: E. **Denny** (Birmingham City U), N. Hudson & H. Mitchell (DeMontfort U), N. Raine-Fenning (U of Nottingham); **£71,255;** https://gtr.ukri.org/projects?ref=ES%2FJ003662%2F1
- Preventing recurrence of endometriosis by means of long acting progestogen therapy: (**PreEmPT**); **NIHR Health Technology Assessment**, 11/114/01, 2013-2021; Grant holding intuition: U of Aberdeen; PI: K. Cooper (U of Aberdeen) Co-I's: E. **Denny** (Birmingham City U), G. Jones (Leeds Beckett), L. Middleton (U o Birmingham), et al., **£1,762,184;** https://fundingawards.nihr.ac.uk/award/11/114/01

## 4. Details of the impact (indicative maximum 750 words)

BCU's social research on endometriosis was pivotal in informing new policy and clinical guidance for the estimated 10% of all women in the UK and Europe living with the condition. This research also shaped wider culture conversations in UK schools, parliament and media surrounding endometriosis awareness and menstruation stigma.

### Shaping Clinical Guidance and Informing Policy

Denny's research informed the *first-ever* national clinical guidelines on endometriosis, the (2017) NICE guidance (NG73) Endometriosis: Diagnosis and Management. The NG73 cites R01-R05 in guidance on information and support provision for women, their partners and family [S01: p. 65-92]. Such provision, according to the NG73, is key to improving women's "quality-of-life and positively affects relationships between healthcare professionals and [women] with endometriosis, as well as [women's] personal family relationships" [S01: p. 91].

The NG73 gives special commendation to BCU's Endocul project [R04], stating that it "highlights that services for minority ethnic women with endometriosis could be improved. It was therefore agreed that this was an important point to highlight in the recommendation" [S01: p. 90]. Thus, the guidance now advises women's cultural backgrounds are considered in practitioners' assessments of women's information and support needs. The Endometriosis SHE Trust Chair and Endometriosis UK's Board of Trustee member, who served during the creation of the NG73, states "Professor Denny's research on women's experiences of endometriosis symptoms, including pain and dyspareunia, and recent research on couple's experiences of the condition, informed NG73 guidance on endometriosis information and support provision for women, their partners and family members. Additionally, Professor Denny's Endocul project informed NG73 recognition of the need to improve services for minority ethnic women living with the condition" [S02]. NG73 guidelines improve treatment and management of this disease for the estimated 1.5 million women in the UK with endometriosis [ibid.].

Denny's research informed international endometriosis clinical guidance, the (2013) European Society of Human Reproduction and Embryology's (ESHRE) *Guidelines on the Management of Women with Endometriosis*. Citing R01, R03, R05, the guidance recommended developing "patient-centred self-management interventions, with a psychosocial element and a multidisciplinary approach, to enable women with endometriosis to more effectively manage the condition and the impact it has upon their daily lives" [S03: p. 28].

BCU research [R01, R04, R05 and additional studies by Denny] informed the (2017) APPG Women's Health Inquiry, *Informed Choice? Giving Women Control of Their Healthcare* [S04]. Citing much of Denny's research, the report highlighted the routine dismissal of endometriosis as 'normal period pain' and recommended the Royal College of General Practitioners (RCGP) and the Royal College for Obstetricians and Gynaecologists (RCOG) introduce new education modules on recognising and treating the condition [S04: p5]. The Women's Health APPG Secretariat states that "the report drew upon a number of endometriosis studies carried out by Professor Denny" and led to a "spotlight on endometriosis," raising awareness about the condition "with health care professionals and the general public to ensure women can access better diagnosis and treatment options across the country" [S05]. The Secretariat further confirms the Inquiry, drawing on Denny's research, led to the RCGP introducing an accredited e-learning module to promote awareness of endometriosis symptoms and the RCOG creating a core knowledge tutorial on pelvic pain and endometriosis for practitioners within and outside of the UK [S05]. The modules are based on the NG73 [S01] and ESHRE endometriosis guidelines [S03], which as established above, are informed by BCU research [R01-R05].

**Informing Conversations and Improving Menstruation Education**

The (2017) APPG Women's Health Inquiry cited numerous studies by Denny, as demonstrated above, to call for school curriculum that includes education about "normal and abnormal menstruation" to help girls and young women "recognise when they need to seek help with symptoms" [S04: p30]. The Women's Health APPG Secretariat confirms [S05] this recommendation led to Department for Education introduction of *Relationships and Sex Education and Health Education* that, for the first time, included mandatory menstruation education [S06]. The curriculum guidance, made compulsory from September 2020 for female and male (where appropriate) primary and secondary students in England, ensures approximately 7.25 million pupils will "be taught key facts about the menstrual cycle including what is an average period" [S06: p 31].

Based on BCU's reputation for social research on endometriosis and menstrual health, Brook, the sexual health service and education charity for young people, and Plan International UK, the international children's charity, commissioned Weckesser and colleagues to create a series of evidence-based resources for the *Let's Talk. Period* initiative. These resources [S07] provide a 'go to guide' for the menstrual health sector, informing Brook's and Plan International UK's national programme with secondary schools and colleges across the UK.

BCU research informs wider public and cultural conversations regarding endometriosis awareness and menstruation stigma. Research by Denny and Weckesser features in multiple articles on endometriosis by high profile media outlets with large national and international readership, including *The Independent, The New Statesmen,* and *The Daily Express* [S08]. This research [R6] and its media coverage were included in the 2019 parliamentary debate on Endometriosis Workplace Support (CPD-2019-0228) [S09: p 6]. To meet the demand for and further these public conversations, Weckesser founded *The VQ Collective*, a women's health public engagement initiative. The VQ collective provides ongoing public engagement events [S10] (including pop up shops with UK-based period pants companies and educators WUKA and Precious Stars, Pint of Science public talks, and University of Oxford podcasts) to tackle the taboos that continue to surround menstrual health and women's sexual and reproductive health generally.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

**S01**: (2017) NICE Guidance NG73: Endometriosis: Diagnosis and Management, https://www.nice.org.uk/guidance/ng73/evidence/full-guideline-pdf-4550371315

**S02**: Testimonial from Endometriosis UK's Board of Trustee/Endometriosis SHE Trust Chair [Named corroborator 001], corroborating impact of Denny's endometriosis research on the NG73

**S03**: (2013) ESHRE External Review: Management of Women with Endometriosis, https://www.eshre.eu/~/media/sitecore-files/Guidelines/Endometriosis/Endometriosis_review-report.pdf

**S04:** (2017) Women's Health APPG Inquiry, 'Informed Choice? Giving Women Control of Their Healthcare',https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/5d41adfc49a80d0001f41b82/1564585493903/Informed+Choice+Report+Final.pdf

**S05**: Testimonial from the Women's Health APPG Secretariat [Named corroborator 002] corroborating impact of Denny's endometriosis research on the APPG Inquiry, including subsequent introduction of:

- RCGP Accredited Online Endometriosis Training, https://rcgpportal.force.com/s/lt-event?id=a1U1i000000CwIYEA0&site=a0d0Y00000AeOP6QAN
- RCOG's Pelvic Pain and Endometriosis: Core Knowledge Tutorial, https://elearning.rcog.org.uk/pelvic-pain/endometriosis

**S06**: (2019) Department for Education, Relationship and Sex Education and Health Education guidance,https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908013/Relationships_Education__Relationships_and_Sex_Education__RSE__and_Health_Education.pdf

**S07:** Corroboration of (2020) 'Let's Talk.Period*'* resources for Brook and Plan International UK

- 'Centring the Voices of Young People' https://plan-uk.org/file/plan-uk-ltp-learning-briefing-1pdf/download?token=F0NCK5lH
- 'Best Practices & Latest Innovations in UK Period Poverty Initiatives' https://plan-uk.org/file/plan-uk-ltp-learning-briefing-2pdf/download?token=XbJhBfCy
- 'Inclusivity & Diversity – UK Expert Views' https://plan-uk.org/file/plan-uk-ltp-learning-briefing-3pdf/download?token=BIB_vIpS
- 'Evidencing & Evaluating Period Poverty Initiatives for Impact' https://plan-uk.org/file/plan-uk-ltp-learning-briefing-4pdf/download?token=_hvDAVcr

**S08:** Corroboration of public debate impact of endometriosis research:

- (2017) 'Endometriosis: Millions of Women Suffering from Chronic Lack of Research' in *The Independent,* by L. Pasha-Robison*;*
- (2017) 'Endometriosis Treatment: More Research Needed to Offer Better Care for Women' in *The Daily Express,* by S. Delgado;
- (2018) 'Why the "Gender Data Gap" Means Doctors Don't Take Women's Pain Seriously' in *The New Statesmen* by C. Criado-Perez

**S09:** (2019) Endometriosis Workplace Support, Parliamentary Debate Pack https://commonslibrary.parliament.uk/research-briefings/cdp-2019-0228/

**S10**: Corroboration of impact of VQ Collective public engagement events:

- March 2018, The VQ Collective Pop Up Shop, in Birmingham's Great Western Arcade
- May 2018, Pint of Science (Birmingham) talk: 'The Vagina Monologues'
- June 2018, University of Oxford podcast: 'Challenging Stigmas around Menstruation, Menopause and Female Sexuality'

*All above sources of corroborating evidence, without direct URL links, are available from the BCU research team. All URL links accessed on 22.03.2021*