

## Witten evidence from Birmingham City University [WRH0005]

Please see our response to the Women & Equalities Committee's call for evidence regarding women's reproductive health. This response is being submitted on behalf of Birmingham City University (BCU).

BCU's endometriosis research shapes national and international clinical health guidelines and policy. The first-ever NICE guidance on endometriosis (2017) cites BCU research to improve care for the estimated 1.5 million women in the UK with the condition. The All Party Parliamentary Group Women's Health Inquiry (2017), 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 continues to inform wider societal conversations about endometriosis and tackling menstrual health inequalities, and Weckesser and Williams were invited to join the Government Office for Equalities Period Poverty Taskforce in 2019 in recognition of their expertise.

BCU has several research outputs that address the following areas of the inquiry, specifically regarding endometriosis and menstrual health:

- What are women's experiences of being diagnosed with, undergoing procedures and being treated for gynaecological or urogynaecological conditions;
- What disparities exist in the treatment and diagnosis of gynaecological or urogynaecological conditions;
- What barriers exist in the treatment and diagnosis of gynaecological or urogynaecological conditions.

We provide a summary of research findings, with references and links to publications and reports, under the headings 'Endometriosis' and 'Menstrual Health'. Key points are highlighted in **bold** text, along with our recommendations for the Committee within the 'Conclusion & Recommendations' section.

### Endometriosis

How endometriosis affects women's everyday lives was not understood before [Professor Elaine Denny's](#) study in 2004 [R01]. This 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.

*"I had specifically been told that it was just part of being a woman, it's just one of those things."* [R01]

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. The study recommended health practitioners investigate women's reported pain more seriously.**

Denny's 2009 study [R02] found **women with endometriosis experience uncertainty about the condition from diagnosis, through the course of the illness and into the future.** The study **evidenced the need for improved patient-practitioner communication, information and support for women to help them manage this uncertainty.**

*"I was seeing a female doctor and I remember thinking great, she will have some sympathy. She just told me all women have to put up with it."* [R02]

Research [R03] from Endometriosis and Cultural Diversity (Endocul): Improving Services for Minority Ethnic Women (2010) was the first in the UK to explore how to improve minority ethnic women's experience of endometriosis and its treatment. The study 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.**

*"It wasn't all in my head, like some doctors would have you believe for years basically they had you believe that it was all in my head and I kept thinking no, so the biggest impact was the fact they finally diagnosed something and it suddenly made sense" [R03]*

Research [R04] from EndoPart: Endometriosis – Improving the Experiences of Couples (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.

*"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." [R04]*

Denny's and [Dr Annalise Weckesser](#)'s qualitative research [R05] for Preventing Recurrence of Endometriosis by Means of Long Acting Progestogen Therapy (PreEmPT) Trial (2018) was the first published study focused on women's **experiences of medical treatments for endometriosis**. The study found **women "feel desperate" and are "willing to try anything" for symptom relief.**

*"I obviously have tried pretty much every treatment for endometriosis before surgery... If something's not worked before, you know, you would as much as [pauses], like say, if a doctor told me to take something just to try it, of course I would want to. But I think sometimes you know your body better ... especially if you've had [the treatments] in the past." [R05]*

In addition to the published research outputs highlighted, in July 2023 BCU convened the British Academy/Wellcome Trust conference: *'Reframing Endometriosis: Power, Politics and Potentials'*<sup>1</sup>. This was the first academic conference to bring together UK and internationally based endometriosis social science and humanities researchers alongside, and in conversation with, prominent (bio)medical researchers, third sector representatives and independent researchers and authors. The conference focused upon the way endometriosis is categorised, in recognition that this is central to how it is understood and experienced. Speakers discussed the historical legacies of endometriosis as a 'wandering womb' induced 'hysteria' and 'career women's disease' and considered the intersecting systems of power and the marginalisation of gendered, racialised, and disabled bodies. **Discussions also explored the socio-cultural-political implications of the latest medical research suggesting endometriosis is a systemic (whole body), rather than a solely gynaecological, disease.**

## References

R01: **Denny, E.** (2004) *Women's experience of endometriosis*. Journal of Advanced Nursing. 46 (6): 641-648 <https://doi.org/10.1111/j.1365-2648.2004.03055.x>

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<sup>1</sup> British Academy/Wellcome Trust Conference [Reframing Endometriosis: Power, Politics and Potential Futures | The British Academy](#) '

R02: **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>

R03: **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>

R04: 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>

R05: **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>

## Menstrual health

BCU's endometriosis research evidences the need for greater education, information and communication around endometriosis, and recognises that this is intrinsically linked to wider menstrual health education and knowledge (or lack thereof). With the increase in awareness of 'period poverty'<sup>2</sup> within the UK, BCU broadened its research to examine the intersections between endometriosis, reproductive and menstrual health, and period poverty.

In 2019, Brook, the sexual health service and education charity for young people<sup>3</sup>, 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 (2019). These resources [R07] provide a 'go to guide' for the menstrual health sector, providing guidance on how to address barriers in the provision of menstrual health education and the provision of free menstrual products, by **centring young people's voices and recognising intersectional diversities to ensure menstrual equality (and subsequently improve reproductive health access).**

*"Inclusivity matters because so many different people are included in this shared experience [of menstruation], but there are so many different individual experiences... The [period poverty] movement itself, no matter how well intended it is there are nuances we will continue to miss along the way unless there is change in terms of who's involved..."[R07, Brief 3]*

The briefs draw on existing research and additional primary research conducted specifically for the project to **provide real life examples of the impact that poor menstrual health education and poor accessibility of appropriate menstrual products can have upon young people and those that need support with their menstrual/reproductive health.**

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<sup>2</sup> 'Period poverty' usually refers to financial difficulties in accessing menstrual products. However, we use the broader term recognised within the menstrual health sector which includes poor access to menstrual products, poor menstrual health education and inadequate menstrual health care/support

<sup>3</sup> 'Young people': Brook provides services for young people up to the age of 25 [Brook | Our work | Level 1 and 2 sexual health](#)

*“In the UK, only 8% of girls (aged 15 to 19) know what the common gynaecological condition endometriosis is; a rate significantly lower than in other countries (24% in Australia (7) and 19% in Italy (8)). The vast majority (86%) of teen girls want to learn about endometriosis, with school being their preferred source, and they think that boys should learn about it too (83%).” [R07, Brief 1]*

Further to the Let’s Talk.Period initiative, [Gemma Williams](#) and colleagues were successfully granted Economic and Social Research Council funding in 2020 as part of UK Research and Innovation’s rapid response to COVID-19. “Periods in a Pandemic: how UK period poverty initiatives have mitigated Covid-19 challenges” examined how Covid-19 impacted upon period poverty and menstrual health support within the UK over an 18-month period.

*“Organisations set up to support people affected by the pandemic are focusing on providing food to keep people alive, but have not understood that menstrual products are also a basic necessity so aren’t providing this as standard”[R08]*

Key findings [R08] show how **the pandemic led to the exacerbation of period poverty within the UK**, caused by the emergence of new groups of women, girls, and people who menstruate, experiencing period poverty (including students and NHS staff), more people being unable to access products from their usual places due to supply shortages and hoarding, the neglect of menstrual products being seen as ‘essential items’ in care packages for those who were vulnerable and shielding, and **increased barriers to accessing menstrual health support and health care** linked to ‘digital poverty’ and changes to GP provision.

*“I’m worried that I may be premenopausal but haven’t felt I can contact the GP. I tried but it was a phone call and I didn’t have the privacy to discuss the issue.” [R08]*

### [Black women’s experiences of menstrual and reproductive health](#)

In 2022, Weckesser and colleagues supported the Black Women’s Reproductive Health Project<sup>4</sup> in publishing the findings of their report in the British Medical Journal [R09].

*“With limited research on racial inequalities in gynaecological care in the UK, best practice guidelines have yet to be conceptualised for menstrual disorders in Black women. However, the Royal College of Obstetricians and Gynaecologists (RCOG) Race Equality Taskforce and FivexMore have established guidelines addressing elevated maternal mortality rates in Black women, and parallels from such guidelines should be drawn on.” [R09]*

Their ‘Call to Action’ provides four key recommendations to support Black women’s menstrual and reproductive health:

- Inclusion of **comprehensive, intersectional menstrual education**, beyond menarche, in primary school education curricula.
- Introduction of **mandatory training for healthcare professionals and those who teach about menstrual health in schools**, covering the historical development of current menstrual health knowledge and attitudes, and the pervasive impact on those who menstruate, with particular focus on racially marginalised populations.
- **Increase in the amount of research investigating the prevalence and impact of menstrual-health related conditions on Black women**, ensuring governing bodies (such as the RCOG) act on emerging evidence when establishing and implementing best practice guidelines.

### **Development and expansion of**

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<sup>4</sup> The Black Women’s Reproductive Health Project: [Black Women Reproductive Health – T.A.P Project \(tappproject.co.uk\)](https://tappproject.co.uk)

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- ‘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\\_vlpS](https://plan-uk.org/file/plan-uk-ltp-learning-briefing-3pdf/download?token=BIB_vlpS)
- R07: **Williams, G., Weckesser, A., & Craddock, E.** (2022). *Periods in a Pandemic: how UK period poverty initiatives have mitigated Covid-19 challenges*. Birmingham City Un **peer support offered by charities and other organisations** which address gynaecological conditions, menstrual health, or period poverty.

## References

- R06: **Weckesser, A., Randhawa, A., Williams, G., & Hewitt, A.** (2019). *Let's Talk.Period. Briefs 1-3*. Plan International UK. Retrieved 07/08/23 from: ‘Centring the Voices of Young People’: <https://plan-uk.org/file/plan-uk-ltp-learning-briefing-1pdf/download?token=F0NCK5IHiversity>. Retrieved 07/08/23 from: <https://bcuassets.blob.core.windows.net/docs/periods-in-a-pandemic-final-report-jan2022-132871415463701935.pdf>
- R08: Perro, D., Seglah, H., Abrahams, V., **Weckesser, A.**, Griffith, VAS. (2022) *Black women's menstrual and reproductive health: a critical call for action in the UK*. British Medical Journal. <https://doi.org/10.1136/bmj.o3052>

## Conclusions & Recommendations

BCU’s research (R01-R05) evidence 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.

It is important to note that **conditions such as endometriosis are not solely gynaecological or ‘reproductive’ in their nature, rather they are chronic, complex, systemic conditions which can affect the whole person**, mentally as well as physically. They therefore warrant a holistic approach in terms of diagnosis, treatment and person-centred care. **We recommend the Committee acknowledge this in their findings and subsequent recommendations.**

We acknowledge that the inquiry does not specifically refer to ‘menstrual health’ however, menstrual health forms a significant part of overall ‘reproductive health’ and the lifespan of cisgender women and girls, trans men and non-binary people who menstruate. We therefore provide our menstrual health research outputs within our submission (R06-R08) to provide evidence of how **menstrual health education, menstrual stigma and shame within society and the accessibility of menstrual products and health care impact upon the reproductive health and wellbeing of women and people who menstruate**. These wider issues are imperative when looking at how women seek and experience support for their reproductive health, particularly when trying to understand barriers that may be experienced. **We recommend the Committee acknowledge this in their findings and subsequent recommendations.**

Finally, we recommend the Committee examines the questions they seek to address with this inquiry in an **intersectional, diverse, and inclusive way to tackle reproductive health inequalities linked to gender, race, disability and other minoritized communities**. Our research provides insight into how such factors impact those who need support for their reproductive health. Addressing such inequalities are crucial to ensure that women and people assigned female at birth receive the health

care they need. **We therefore strongly recommend the Committee incorporates the 'Call to Action' to better support Black women's menstrual and reproductive health [R08] within their findings and subsequent recommendations.**

We would be happy to provide further evidence or advice/guidance in support of this inquiry, based upon our research expertise.

***August 2023***