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Endo@Western: co-designed endometriosis and chronic pelvic pain guidance for WSU staff

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Recommendations

- → Endo@Western guidance documents: an update to existing policies and processes

  - Generated using a rigorous co-design process, the project team has created an Endo@Western guidance document. The guidelines involve existing policies and processes at Western Sydney University (see Section 1(5)). Any new/additional proposed policies or processes are highlighted in the text.
  - WSU academic and professional staff involved in the development process have confirmed that amendments offered in the guidance document will enable them to better manage their endometriosis symptoms and chronic pelvic pain in ways that enable them to maintain their productivity and engagement at work.

- → Chronic Pelvic Pain advocate

  - Utilising the existing School/Institute/Division's Equity and Diversity Working Party's (EDWP) each committee will nominate a Chronic Pelvic Pain Advocate (CPPA).
  - The nominated advocate will provide guidance to employees about relevant institutional information and resources.
  - The opportunity to speak with an informed colleague, potentially with lived experience, can contribute to more open conversations, creating a more inclusive workplace culture, a key goal identified during co-design.
  - This person/s will be approachable, a member of an EDWP (with workload acknowledgment). The CPPA is not a medical professional and will not medical advice or long-term emotional support. The advocacy roles primary focus is on providing information and direction to existing and appropriate institutional supports.

- → Promote Endo@Western Toolkits among staff and supervisors

  - The co-design process has contributed to the development of two toolkits:
    a. **A Toolkit for Supervisors**: Supporting staff with Endometriosis and Chronic Pelvic Pain in the workplace.
    b. **A Toolkit for Staff:** Supporting staff with Endometriosis and Chronic Pelvic Pain in the workplace.
  - The toolkits are a practical resource to assist supervisors and staff on how to support employees with chronic pelvic pain and/or endometriosis in the workplace. This initiative is evidence-based to improve the productivity and well-being of staff and should be disseminated via OECD and EDWP's
  - The toolkit intends to meet employer operational needs and materially support employees managing endometriosis and/or pelvic pain

Executive Summary

Women and people who menstruate – particularly those diagnosed with endometriosis and chronic pelvic pain – may be disadvantaged at Western Sydney University (WSU). Research conducted with WSU staff and supervisors has found that most staff with endometriosis and chronic pelvic pain have experienced symptoms that negatively impacted their workplace engagement, productivity, and wellbeing. Overwhelmingly, they don't feel comfortable speaking to male supervisors or colleagues regarding how their work is impacted by their condition and as a result lack information, support, and reasonable adjustments to manage their symptoms.

The majority (62%) of WSU staff members are women and will likely at some point of their employment manage menstruation, menstrual disorders and/or menopause. Gynaecological and menstrual conditions, such as dysmenorrhea—characterized by period pain without any identifiable physical changes in the pelvis—affect up to 90% of women and individuals presumed female at birth (PFAB). Similarly, endometriosis, a chronic inflammatory disorder that affects the whole body, impacts approximately 11-14% of this population (these prevalence statistics are in line with or significantly greater than conditions such as asthma (11%), diabetes (4%), and heart disease (4%)). Chronic pelvic pain, an umbrella term used to encompass a range of conditions, including (but not limited to) endometriosis, vulvodynia, painful bladder syndrome, adenomyosis, and chronic pelvic inflammatory disease – is incredibly common.

Previous scholarship has demonstrated the significant impact of endometriosis and chronic pelvic pain on workplace productivity, career derailments, career deferment, and early retirement. In response to this the authorship team has undertaken a significant body of work to co-design a set of employer guidelines to support people to manage their endometriosis and chronic pelvic pain symptoms so they are able to work productively and thrive in their workplace.

This research sought to extend this initial work and draw on WSU as a case study for how guidelines could work in the Australian higher education setting. The project refines and provides recommendations tied to how the developed guidelines and suggested practices can be integrated within and across existing WSU policies.

This report presents compelling evidence that WSU staff would benefit from a set of endometriosis guidelines. We demonstrate how guidelines may improve issues relevant to disclosure and inconsistent access to support based on supervisors' knowledge and practice.

In response, the authors have co-designed an Endo@Western guidance document, which draws from existing and proposed policies and processes that staff have confirmed enable them to better manage their endometriosis and chronic pelvic pain symptoms while working productively. We utilise the existing Equity and Diversity Working Party's (EDWP) and propose that each committee nominate a Chronic Pelvic Pain Advocate (CPPA). Finally, through our co-design process, we have developed two toolkits (A Toolkit for Supervisors & a Toolkit for Staff) as practical resources to assist supervisors and staff in supporting employees with chronic pelvic pain and/or endometriosis in the workplace. This initiative is based on evidence that has demonstrated improvement in productivity and well-being for staff and the institution.

By publishing this report, we advocate for the voices and lived experiences of staff at WSU. By offering guidance documents and supplementary toolkits, we intend to enable the University to integrate policies, education, and processes into the daily routines of WSU staff, enabling them to effectively manage their symptoms and thrive in their roles.

Itemised Budget Expenditure

Total funded amount $ *4956.03*

Date	Activity / Item	Cost (GST incl.)
March-November	Personnel: Research Assistance HEW Level 5, 70 hours* Step 1	$3,756.03
June	Focus group transcript costs (Happy Scribe 6-month subscription)	$1200
Total expenditure:		**$4956.03**

Introduction and Background

Women constitute 62% of WSU's workforce. Accordingly, most of WSU's employees will likely at some point through their employment manage menstruation, menstrual disorders, and/or (peri)menopause.

Prior scholarship has demonstrated that gynaecological and menstrual disorders (i.e. endometriosis) are common (affecting >90%[1] and >14%[2] respectively) and significantly impact work attendance and productivity[2-6]. Endometriosis (a focus of the present research) affects one in seven women aged 44-49[7] leads to an average of 4 sick days per month, along with significant reductions in productivity (presenteeism)[8]. Indeed, research suggests that 84% of the $9.7B yearly cost of illness burden in Australia associated with Endometriosis is due to lost productivity[9].

Recent scholarship has found:

- 1 in 10 people with endometriosis will lose their employment due to managing the disease.
- 1 in 3 will be overlooked for a promotion.
- 70% must take unpaid time off work to manage symptoms.
- 50% said lack of workplace flexibility was a significant problem.

Our prior research also demonstrates how for employees managing endometriosis and/or chronic pelvic pain relatively small changes at work (reasonable adjustments) can contribute to improved symptom management and increased employee productivity [9]. Leading from this prior work the team secured a partnership grant with Endometriosis Australia, the peak body for endometriosis, to develop a set of workplace guidelines for employers to support those with endometriosis in the workplace – titled "Endo@Work".

The Endo@Work research team has undertaken a significant body of work to co-design a first draft of these workplace guidelines, involving:

- a global scoping review of existing workplace guidelines relevant to menstruation, menstrual disorders, and menopause.
- online survey (yielding 398 responses) to understand people's workplace experiences managing endometriosis in Australian contexts.
- Six focus groups with employees facilitating a semi-structured discussion about their experiences of endometriosis at work and how it might be improved by a set of guidelines.

Extending this initial work and drawing on the WSU context as an industry leading case study, the present research is concerned with the co-development of a set of guidelines for this institutional setting “Endo@Western” while also considering their utility in the Australian higher education setting.

The project refines and provides recommendations tied to how the developed guidelines and suggested practices can be integrated into existing WSU policies. These outcomes were achieved through targeted focus groups (current WSU academic and professional staff managing endometriosis and/or chronic pelvic pain) and staff responsible for the management/supervision of employees/work units (managers, HR).

There are significant individual and organisational benefits associated with this work. Identifying and prioritising what the University can do to support staff managing endometriosis symptoms (and other gynaecological and menstrual disorders such as chronic pelvic pain more broadly) can reduce absenteeism, and improve work productivity, employee well-being, and satisfaction at WSU. Furthermore, this project is industry leading in the higher educational sector and supports WSU’s status as a pioneer for workplace gender equity.

Project Aims

This project aims are to:

1. Document existing policies & identify current endometriosis (or other gynaecological or menstrual disorders) support needs at Western.
2. Gain feedback on the draft/proposed Endo@Work guidelines and how they can appropriately amended/ integrated across existing WSU HR practices; and
3. Co-develop best practices for implementation and accessibility (e.g., web-based resources, videos, etc.) of Endo@Western guidelines.

Methodology

Through semi-structured in-depth interviews and focus groups the project privileges the lived experiences and voices of WSU employees managing endometriosis symptoms and chronic pelvic pain at work. Upon receiving ethical approval from the Western Sydney University Human Ethics Committee (Approval H15537) in March 2024, the project team initiated this exploratory qualitative study by establishing a project steering committee.

Initially, the steering committee was asked to sense check and formally review the prior codesigned draft Endo@Work guidelines. The group provided feedback regarding the feasibility and appropriateness as it relates to WSU's existing policies and processes. Arising from this institutionally specific feedback, the guidelines were amended to form a first draft of the Endo@Western guidelines.

The steering committee was comprised of seven cis women with a diagnosis of endometriosis and/or chronic pelvic pain across both academic and professional foci at WSU (Table 1).

Table 1. Demographics of Steering Committee N=7

		N	%
Gender	Woman	7	100%
	Men	0	-
Focus	Academic	4	57%
	Professional	3	43%
	Technical	0	-

Recruitment

Purposive sampling was employed to recruit participants. A recruitment email was distributed by each School/Institute's manager to their respective academic, professional, and technical workforce. Inclusion criteria incorporated individuals over the age of 18 who currently reside in Australia and are either: employees of WSU with a diagnosis of endometriosis and/or chronic pelvic pain or are currently employed as supervisors/managers at WSU.

A total of 9 people, 8 (cis) women and 1 (cis) man, participated in 2 focus groups and 2 interviews (Table 2). Of these, 4 participants were employees (not in management, supervisory, or HR roles) with a diagnosis of endometriosis and/or chronic pelvic pain. Of the participants, 5 were supervisors at WSU - one of whom had a diagnosis of endometriosis – while the others did not have a diagnosis of endometriosis and/or chronic pelvic pain.

Table 2. Demographics of Focus Groups and Interview Participants N=9

		N	%
Gender	Woman	8	89%
	Men	1	11%
Role	Staff	4	44%
	Supervisor	5	56%
Focus	Academic	8	89%
	Professional	1	11%
	Technical	-	-

Diagnosis	Endometriosis	4	44%
	Chronic Pelvic Pain	1	11%
	None	4	44%

Data Collection

Data was collected in April 2024 through 2 interviews and 2 focus groups. The first interview featured a WSU supervisor with an endometriosis diagnosis, offering insights from both an employee and a supervisory perspective. The second interview was conducted with a supervisor who did not have an endometriosis diagnosis. One focus group consisted of 3 WSU employees experiencing endometriosis and/or chronic pelvic pain, while the other comprised 4 WSU staff members in managerial, supervisory, or HR positions.

Participants were asked to review the first draft of the Endo@Western guidelines, providing their feedback on existing processes and policies, successes and barriers to accessing support, and their recommendations for additional education and support.

Each interview and focus group session lasted between 60 and 90 minutes. All sessions were audio-recorded and transcribed verbatim using the AI tool HappyScribe. Transcripts were then reviewed and de-identified by a member of the project team.

Data Analyses

An iterative thematic inquiry (ITI) approach was drawn on to analyse the qualitative data [10]. ITI emphasises the researcher's dual responsibility to identify patterns within the data and effectively convey these patterns to the intended audience. Central to this approach is the idea that themes, which serve as the foundation for both data analysis and the presentation of findings, should be developed continuously unlike traditional methods that delay thematic exploration until the later stages of a project.[10]

Following each interview and/or focus group discussion, authors MO and DH engaged in a review of the themes discussed and how these themes shape the further design of Endo@Western guidelines and the processes and education required for the WSU institutional context. In September 2024 key themes and a final draft of the guidelines were reviewed by the Steering Committee; followed by a final round of ITI and changes to the guidelines and education documents (Appendices A- D are a result of the research and discussions with staff and supervisors at WSU).

Findings

Several key themes were identified and are hereafter positioned as:

"Barriers to conversations and disclosure in the workplace" - employees consistently discussed how their supervisor's gender affected their willingness to disclose their endometriosis diagnosis and/or symptoms. Participants were more likely to disclose their diagnosis to a woman supervisor and interpreted how reasonable accommodations including working-from-home requests and use of leave entitlements were also more likely supported by a woman supervisor. For example, Maria (employee) remarked how:

> *"My direct supervisor is a woman ...I would feel ... more comfortable than if it was a man. She's very supportive and understanding. I have ... no fear of embarrassment".*

Amy reflected on disclosing her diagnosis and symptoms to male supervisors:

> *"Those initial conversations are really difficult ...the initial conversation with the men ... they just cannot appreciate what we go through or they're uncomfortable with these conversations. Because I was taking sick leave on a monthly basis, sometimes there would be questions about my absenteeism or my lack of attendance on campus and my preference to work remotely. Those initial conversations are really difficult".*

Conversely, one male supervisor stated that:

> *"What was more surprising for me and more concerning ... was when some women ... said that they did not get treated any better by their female managers... it seems that there is this attitude as in, I've been through that with no problem, so you shouldn't".*

(b) **Perspectives on endometriosis as a disability:** A second theme emerging from the data related to the classification of endometriosis as a disability. Focus-group participants presented diverse perspectives on the classification revealing a tension between the desire for increased support and the potential implications for individuals with endometriosis and other chronic conditions. Participants acknowledged that recognising endometriosis as a disability could create essential support pathways, such as workplace adjustment plans and advocacy initiatives, aimed at assisting affected staff members.

At once participants interpreted how classifying endometriosis as a disability may have undesirable consequences for sufferers' professional identities, and career aspirations and may impact their autonomy in the workplace concerning disclosure. Accordingly, Elle (Supervisor) interpreted how:

> *"It's about choice at the end of the day … some people might identify that experience as a disability. Some people might not want to. How you frame the supports that are offered to people is important." (Elle, Supervisor).*

(c) **Current and future workplace support**- participants interpreted how access to existing institutional supports was closely tied to colleague and supervisor knowledge and awareness. Participants reported mixed experiences with several employee's attributing the support they received to "luck" and "fortune". For example, Kiera (Employee) remarked:

> *"I'm very fortunate to work in a really lovely team, and they're all women, and we are very supportive of each other, so the conversations are quite easy".*

Other respondents discussed how current policies and institutional practices made it difficult to take up supports. For example, periods of absence owing to symptoms and or required treatments (i.e. surgical procedures or tests) were especially problematically. Participants felt pressured to get back to work and so not recovering appropriately. Others reflected on having to make up for time away together with pushing through pain and other symptoms because there was no alternative:

> *"You can't just drop the ball and someone's there to pick it up … unless you've got a really tight teaching team." (Rachel, Supervisor).*

> *"I didn't want to make up for lost time on weekends or after-hours…I feel like there could be more equitable measures put in place to understand that people's performance can be impacted by this as you're trying to manage the condition [Endometriosis]"*
> *(Amy, Employee).*

Related to the variability in support and challenges in taking up reasonable adjustments (Rachel, Amy, and Kiera), supervisor knowledge was identified as problematic and requires addressing. Participants suggested that standardising support could be achieved through educational resources tailored for staff and leaders. Participants interpreted that addressing the educational gaps within organisations is essential for creating an inclusive and supportive environment for all employees. Suggestions offered by supervisors and participants included:

> *"[A] health literacy training resource that provides examples of conditions that people might experience but focuses on the fact that these experiences aren't always continuous or it's like in phases, it might be flare-ups, it might be cycles. Then some of the examples*

> *of how people might need accommodations or have particular requirements" (Yasmine, Supervisor).*

Participants advocated for the establishment of workplace-appointed advocates within OECD or WHS allied departments. These officers could function as essential intermediaries, ensuring that employees are heard and supported:

> *"What would be more helpful is just to have an equity officer who works with your managers, works with you, to figure out what your requirements are, what's going to make your work as productive as it could be, within the means that you have" (Amy, Employee).*

> *"It would really make sense to potentially approach the Equity & Diversity Working Party … to have that representative as part of that committee. That means that you've got that representative there who can speak on behalf of anybody within the school who may be suffering" (Rachel, Supervisor)*

(D) **Co-developed Endo@Western guidance and implementation**-participants were in favour of workplace guidance and resources detailing the impact of endometriosis on workplace performance and how to effectively support employees so their productivity and engagement in the workplace were not diminished. However, employees acknowledged the complexities of workplace guidelines and stated that Endometriosis should not be treated differently from other chronic conditions. Employees added the caveat that, unlike diabetes, there is a stigma and taboo tied to the condition. Relatedly, they discussed how knowledge of the condition, and its nuanced effects remain low despite increased attention.

Regarding the co-developed draft guidance, future-proofing the guidelines by creating more generalised directives and an "umbrella policy" was suggested. For example, Thomas remarked:

> *"The content itself … it's pretty comprehensive. If anything, I wonder if there is such a thing as being too comprehensive… my recommendation is to think about future-proofing the policy. And oftentimes, this means not going into too many specific details about anything but start with the general principles and stick to the general principles that would be applicable to those practical examples, but not writing practical examples per se" (Thomas, Supervisor).*

Conclusion

This study has built an evidence base concerning the experiences of WSU employee's managing endometriosis symptoms and work. We have gained feedback from managers and supervisors who are or might be required to support employees with an endometriosis diagnosis/chronic pelvic pain. We have co-developed guidance documents "Endo@Western" guidelines that can be usefully integrated within and across existing WSU policies and practices to improve the productivity and workplace experience of those with Endometriosis or CPP.

Appendices

- → *APPENDIX A –ENDO@WESTERN AND CHRONIC PELVIC PAIN GUIDELINES*
- → *APPENDIX B –CHRONIC PELVIC PAIN ADVOCATE ROLES AND RESPONSIBILITY*
- → *APPENDIX C – TOOLKIT FOR SUPERVISORS*
- → *APPENDIX D – TOOLKIT FOR STAFF*

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