PE2204/B: Create a national database to record patient outcomes for endometriosis treatments

Petitioner written submission, 5 January 2025

1. Introduction

This written submission supports Petition PE2204, which calls for the creation of a national database to record patient outcomes for endometriosis treatments. It draws on my 36 years of lived experience and on international evidence demonstrating that structured outcomes data improves safety, consistency and quality of care.

2. Summary and Rationale

Despite affecting at least 1 in 10 women and people assigned female at birth, Scotland does not collect national outcomes data for endometriosis. As a result, clinicians lack reliable evidence on:

- treatment effectiveness,
- treatment-related harm,
- complications and disease progression,
- and which patient groups are at highest risk of treatment failure.

This absence of data drives inconsistent care, avoidable complications and continued reliance on trial-and-error treatment. It also contributes to patients feeling dismissed when reporting worsening symptoms, as clinicians lack the evidence needed to validate or explain these experiences.

Scotland already maintains national registries for cancer, diabetes and other conditions, demonstrating that the infrastructure exists. A national endometriosis outcomes database is therefore both feasible and urgently needed.

As founder of Endo Warriors West Lothian, I support over 1,300 women. The same patterns recur consistently: significant side effects, uncertainty about treatment effectiveness and no mechanism to record outcomes. In the absence of national data, patient communities often provide the only real-world insight, revealing systemic issues that remain invisible within the health system.

3. Lived Experience Evidence

I have lived with endometriosis for 36 years and undergone multiple medical and surgical treatments, including a pelvic clearance. Despite severe disease and subsequent complications, my long-term outcomes have never been recorded.

3.1 Treatment Without Data

Following radical excisional surgery for advanced endometriosis, including removal of my uterus, ovaries, fallopian tubes and affected pelvic ligaments, I was prescribed letrozole - a drug primarily used in the treatment of advanced breast cancer - due to the absence of clinical guidance for post-menopausal endometriosis. I was explicitly informed that no evidence base or outcomes data existed to support this decision, and my response to treatment remains unrecorded.

3.2 Lack of Monitoring

Despite recognised risks associated with long-term aromatase inhibitor use, I received no routine monitoring, bone density scanning or structured follow-up. I later developed high cholesterol and required gallbladder removal, yet none of these outcomes were formally captured.

3.3 Device- and HRT-Related Complications

My cervix was healthy following pelvic clearance in 2015. In 2021, pathology confirmed deep endometriosis and my cervix had to be removed. I strongly believe vaginal oestrogen (E-string) contributed to disease progression, yet no outcomes were recorded and no patterns can be identified to inform safer future care.

Across the wider community, similar issues are repeatedly reported, including Mirena coil embedment in rectovaginal disease, HRT-related symptom worsening and significant side effects from repurposed cancer drugs. None of these outcomes are captured at a national level.

3.4 Systemic Consequences

Without outcomes data, Scotland cannot understand treatment failure, identify harm early, optimise clinical pathways or deliver personalised care. This perpetuates under-recognition and patient distrust, not due to clinician indifference, but due to absence of evidence.

4. Government-Acknowledged Data Gaps

The Scottish Government has acknowledged “clear gaps” in women’s health data. This petition directly addresses that gap by proposing a practical and proportionate solution. Dismissing the proposal solely on cost grounds is short-sighted, as improved outcomes data would reduce long-term expenditure associated with repeat surgeries, ineffective treatments and unmanaged disease progression.

5. International Evidence

Several countries demonstrate both feasibility and impact of structured endometriosis data collection.

- Australia: The NECST Registry tracks diagnosis, treatment and outcomes, contributing to reduced diagnostic delays.
- Denmark: Endometriosis data are integrated into national registries, linking surgery, pathology and fertility outcomes.
- Sweden: Quality registries track complications, treatment effectiveness and quality-of-life outcomes, improving clinical guidance.

EU bodies including ESHRE consistently emphasise harmonised reproductive health data as essential for equity, safety and service improvement.

6. ENDO1000 and MHRA Are Not Substitutes

I am an ambassador for ENDO1000; however, it is a research project, not a clinical outcomes registry. It cannot provide national audit, service evaluation or Health Board comparison.

Similarly, the MHRA Yellow Card scheme relies on individual adverse event reporting and does not capture treatment failure, symptom worsening or disease progression. After decades of complex care - including pelvic clearance, permanent chemical menopause and treatment with repurposed cancer drugs - none of these outcomes have been recorded within endometriosis care. This is the gap my petition seeks to address.

7. Economic and Workforce Impact for Scotland

Endometriosis affects women and places a significant burden on Scotland’s economy through sickness absence, reduced productivity, loss of employment and repeated NHS utilisation. Delayed diagnosis and ineffective treatment pathways increase long-term healthcare costs while pushing many individuals out of the workforce.

A national outcomes database would support earlier diagnosis, reduce unnecessary repeat interventions and enable more effective treatment selection. This would help more people remain in work, reduce avoidable demand on NHS services and align with Scotland’s workforce participation and NHS recovery objectives. In this context, improved outcomes data represents a cost-avoidance and productivity-protecting investment rather than an additional burden on public finances.

8. Conclusion

A national endometriosis outcomes database would enable safer, evidence-based care, reduce preventable harm, support earlier diagnosis, improve patient trust and align Scotland with international best practice. My experience, echoed by thousands across Scotland, highlights the human cost of operating without data. This petition presents a practical, achievable solution that would benefit patients, clinicians and policymakers for generations.

I respectfully urge the Committee to support the creation of a national endometriosis outcomes database.