Citizen Participation and Public Petitions Committee
Wednesday 21 January 2026
2nd Meeting, 2026 (Session 6)

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

Introduction

Petitioner	Candice McKenzie
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to create a national database to record patient outcomes for medications, hormone replacement therapy (HRT) and all other hormone therapies used to treat or manage endometriosis.
Webpage	https://petitions.parliament.scot/petitions/PE2204

1. This is a new petition that was lodged on 3 November 2025.

2. A full summary of this petition and its aims can be found at **Annexe A**.

3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.

4. Every petition collects signatures while it remains under consideration. At the time of writing, 1,256 signatures have been received on this petition.

5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.

6. The Committee has received submissions from the Scottish Government and Petitioner, which are set out in **Annexe C** of this paper.

Action

7. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee
January 2026

Annexe A: Summary of petition

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

Petitioner

Candice McKenzie

Date Lodged

3 November 2025

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to create a national database to record patient outcomes for medications, hormone replacement therapy (HRT) and all other hormone therapies used to treat or manage endometriosis.

Background information

There is no national record tracking outcomes. Women are placed on drugs for months or years — often more than once — without an evidence base on effectiveness, side effects or long-term impact to support informed decision-making. We deserve transparency, data and accountability in our care. Women's health should not exist in silence or guesswork.

This petition is not anti-treatment — it is pro-evidence and pro-patient safety. We need a national database to ensure every person with endometriosis receives care guided by real outcomes, not assumptions.

I have personally been on these drugs for years, and I have never been shown any evidence of success rates, risks, or long-term impact. This would never be accepted in any other area of medicine.

It's time to change that.

I'm calling for a mandatory national database to track real-world outcomes of endometriosis treatments and HRT. Women's health deserves evidence, not silence.

Annexe B: SPICe briefing on PE2204

SPICe The Information Centre
An t-Ionad Fiosrachaidh

Calling on the Scottish Parliament to urge the Scottish Government to create a national database to record patient outcomes for medications, hormone replacement therapy (HRT) and all other hormone therapies used to treat or manage endometriosis.

Introduction

Endometriosis is a long-term condition where tissue similar to the lining of the womb is found elsewhere in the body. The symptoms can be debilitating and impact on relationships, work, education and mental health.

It is estimated that 1 in 10 women of reproductive age suffer from endometriosis and infertility can affect between 30-50% of them. It is the second most common gynaecological condition in the UK but the average time to diagnosis is 8 years and 10 months. The cause of endometriosis is not known and there is no definite cure.[1]

Treatment for endometriosis typically consists of:

- Pain management
- Hormone treatments
- Pain relief

The petition specifically refers to the use of drug treatments such as hormones and claims there is a lack of evidence around their use in endometriosis.

Clinicians are responsible for monitoring the effect of any treatment on an individual patient. However, for more robust evidence at a population level, this would require larger scale clinical research.

In order to gain a licence to market a medicine for a particular condition, pharmaceutical companies have to submit results from clinical trials. This should include evidence of safety and efficacy. Post authorisation however, the evidence base is largely informed by academic research.

This research is often reviewed when clinical guidelines are being developed to ensure that clinicians are practising in line with the best possible evidence base.

Scotland follows the NICE Guidance NG73 on Endometriosis: diagnosis and management which outlines best practices in endometriosis diagnosis, referral, pharmacological treatment, surgical management, and care coordination.

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[1] Endometriosis UK – Facts and Figures

This guidance has been used by NHS Scotland to develop the Endometriosis Pathway which details the investigation and management of patients, including treatments such as surgery and hormonal treatments.

Attached to the NICE guidance is also the evidence on which it is based. When guidelines are reviewed, the evidence is updated and new evidence will be used to inform any changes.

NICE has also produced a comprehensive document detailing its strategy for reviewing the research, as well as how it goes about grading the quality of the research.

In addition to this, NICE guidelines also contain recommendations for research when it identifies gaps in the evidence base. The latest guidelines contain a specific recommendation for more research on 'Hormonal treatment for people with endometriosis where fertility is a priority' (see page 33).

The Scottish Government does not typically carry out this type of research itself but it does make funding available via the Chief Scientist Office.

Scottish Government Action

In 2021, the Scottish Government published the 'Women's Health Plan: A plan for 2021-2024' which aims to address women's health inequalities. Prof Anna Glasier was also appointed as the Women's Health Champion in 2023.

Endometriosis is a priority in the plan and specific actions from the plan included:

- £25,000 funding in 2020 to 2021 to commission Endometriosis UK to investigate why the NICE guideline on Endometriosis is not being consistently followed in Scotland and produce a report which detailed the findings.
- £15,000 funding to Endometriosis UK in 2022 to develop a survey to better understand the needs of those who are newly diagnosed and those awaiting diagnosis and to conduct two webinars for those newly diagnosed in Scotland
- £25,000 campaign with Young Scot to increase young people's awareness of endometriosis. The campaign primarily targeted those aged 11 to 25 in Scotland and provided information and education resources on how to support a young person who is in the process of diagnosis or who may have already been diagnosed with endometriosis.

There have been no specific commitments around monitoring the outcomes of endometriosis treatment or the creation of a national database.

The final report of the plan was published in November 2024 and the next phase of the plan is due to be published in January 2026.

Kathleen Robson
Senior Researcher – Health and Social Care
11 November 2025

Annexe C: Written submissions

Scottish Government written submission, 26 November 2025

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

Does the Scottish Government consider the specific ask[s] of the petition to be practical or achievable?

The proposal set out in the petition would be a positive but also very substantial project to gather data over the long term on the health of women with endometriosis.

The creation of a national database of this scale and complexity would have significant costs attached for development and implementation, as well as considerable implications for clinical staff time. On-going training would also be required to ensure consistent, accurate recording of information by a workforce that will change over time. A routine audit may also be required to monitor data quality.

We consider that there are other mechanisms by which we can achieve a shared ambition that those living with endometriosis are able to access the best possible care and support and that they benefit from healthcare services that are safe and effective.

What, if any, action the Scottish Government is currently taking to address the issues raised by this petition, and is any further action being considered that will achieve the ask[s] of this petition?

Women's Health Plan

Scotland was the first country in the UK to publish a Women's Health Plan in August 2021. The Plan sets out actions which aim to address women's health inequalities by raising awareness around women's health, improving access to health care for women throughout their lives, and reducing inequalities in health outcomes for women and girls.

We have taken action through the Women's Health Plan to support both women and health professionals to learn more about endometriosis, the symptoms and treatment options. More information about the progress to date can be found in the Women's Health Plan Final Report pages 25 – 30 may be of particular interest.

We are committed to ensuring that those living with endometriosis are able to access the best possible care and support and that they benefit from healthcare services that are safe, effective and put people at the centre of their care.

That is why menstrual health, including endometriosis, will continue to be an area of focus in the next phase of the Women's Health Plan is due for publication in January 2026.

Phase 2 of the Women's Health Plan will continue action to improve the collection and use of data as there are clear gaps in routine women's health data.

Women's Health Research Fund

The establishment of a Women's Health Research Fund is a long term action set out in the Women's Health Plan to work towards closing gaps in scientific and medical knowledge in women's health. The Fund will focus specifically on menstrual health and gynaecological conditions, menopause, pelvic floor health and healthy ageing and long-term conditions.

Scottish Government has committed £250,000 to the Fund which is being set up in partnership with the charity 'Wellbeing of Women'.

Current Endometriosis Research

The Scottish Government have funded a number of endometriosis research projects to establish more effective treatment and management options for the condition, with the ultimate aim of working towards a cure for endometriosis. A list of relevant projects is provided as an Annex.

Through the Chief Scientist Office, we will continue to invest in health research providing funding for grants and fellowships.

In addition, there is a UK-wide research project based in the University of Edinburgh ENDO 1000 that aims to collect data and biological samples from 1000 individuals with endometriosis over an extended period of time, essentially creating a small scale database.

Researchers hope that building a detailed picture of how lifestyle choices, surgery and medical treatments impact endometriosis symptoms will support development of treatment guidelines that are more likely to be effective for individuals with the disease.

Is there any further information the Scottish Government wish to bring to the Committee's attention, which would assist it in considering this petition?

Current Treatment

There is currently no cure for endometriosis. Medical treatments manage the symptoms caused by the disease and can supress the endometriosis lesions, while surgical interventions are used to remove areas of endometriosis.

It is important to note that following both medical and/ or surgical interventions endometriosis and associated symptoms can return and the disease can progress over time.

NICE Guidelines

The National Institute for Health and Care Excellence use the best available evidence, including on the safety and efficacy of treatments, to develop guidance to improve health and social care. Guidelines are reviewed if there is new evidence that is likely to change the recommendations. The Endometriosis guideline aims to provide clear advice on referral, diagnosis and the range of treatments available.

An Endometriosis Care Pathway has been developed for NHS Scotland, adapted from NICE guidelines and will be updated to take account of revised guidelines.

Safety and efficacy of medicines

The regulation for the licensing, safety and efficacy of medicines is reserved to the UK Government and is the responsibility of the Medicines and Healthcare products Regulatory Agency (MHRA).

Before a company can place a medicine on the market in the UK it has to obtain regulatory approval. To gain approval, companies must submit data demonstrating the quality, safety and efficacy of the medicine in terms of treating a specified condition.

In Scotland, licensed medicines are appraised by the Scottish Medicines Consortium (SMC).

The SMC does this independently of Ministers, which is important because it means decisions on whether to accept newly-licensed medicines are based on clinical and cost-effectiveness at a national population level for all Scotland.

Side Effects

The MHRA tries to ensure that all known side effects of licensed medicines are documented so that patients, doctors, nurses or pharmacists are informed about them. However, it is not possible to predict which individuals may be at risk or when side effects may occur.

The “yellow card” scheme is UK wide and seeks to monitor the safety of all healthcare products in the UK to ensure they are acceptably safe for patients and those that use them. The reports are used to identify side effects and other problems which might not be known about before and if a new side effect is found, the MHRA will review the way the medicine can be used as well as the warnings that are given to people taking it.

Women’s Health Plan Team

Annex

Endometriosis Research Funded by Scottish Government

- The Scottish Government collaborated with Wellbeing of Women on a £250,000 research call in 2022. The research (EPIC2) will primarily be run by researchers at The University of Edinburgh and will look at a non-hormonal drug in the management of endometriosis-associated pain.

- In January 2023 the Chief Scientist Office announced funding of £299,509 for the 30 month ENDOCAN project, led by researchers at The University of Edinburgh. Through a large scale UK-wide trial, the research will investigate whether a cannabinoid can reduce endometriosis-associated pain.

- CSO also buys into UK-wide research funding programmes administered by the National Institute for Health and Care Research (NIHR) – this allows researchers based in Scotland to apply for funding – For example Professor Andrew Horne at University of Edinburgh is the lead researcher on the following project funded by the NIHR Health Technology Assessment (HTA) programme - NIHR HTA (£2,057,700) 2020-2025 ESPriT2: *A multi-centre randomised controlled trial to determine the effectiveness of laparoscopic treatment of isolated superficial peritoneal endometriosis for the management of chronic pelvic pain in women*

- In 2023 CSO announced funding of £299,999 for the MAC-ENDO project. Led by researchers at the University of Edinburgh, this is a proof-of-concept and feasibility study of macrophage-targeted immunotherapy in the management of endometriosis-associated pain.

- In 2024, CSO announced an award of an Early Postdoctoral Fellowship to Dr Lucy Whittaker at the University of Edinburgh (funding of £549,028). This 3 year Fellowship will focus on novel non-invasive diagnostic imaging of endometriosis using total-body PET-CT.

Petitioner written submission, 5 January 2025

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

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.