Public Petitions Committee
Thursday 19 November 2026
6th Meeting, 2026 (Session 7)

PE2253: Create a national database to record outcomes for all endometriosis treatments, surgery and HRT

Introduction

Petitioner	Candice McKenzie
Petition Summary	Calling on the Scottish Parliament to urge the Scottish Government to establish a mandatory national database to record and monitor real-world outcomes from endometriosis treatments, surgery, hormone therapies and HRT, in order to improve patient safety, informed consent, clinical understanding and accountability in endometriosis care across Scotland.
Website	https://petitions.parliament.scot/petitions/PE2253

1. This is a new petition that was published on 9 September 2026.

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

3. Every petition collects signatures while it remains under consideration. At the time of writing, 346 signatures have been received on this petition.

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

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 the 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
November 2026

Annexe A: Summary of petition

PE2253: Create a national database to record outcomes for all endometriosis treatments, surgery and HRT

Petitioner:

Candice McKenzie

Date published:

09 September 2026

Petition summary:

Calling on the Scottish Parliament to urge the Scottish Government to establish a mandatory national database to record and monitor real-world outcomes from endometriosis treatments, surgery, hormone therapies and HRT, in order to improve patient safety, informed consent, clinical understanding and accountability in endometriosis care across Scotland.

Background information:

I have lived with endometriosis for decades & undergone multiple treatments, including hormone therapies, suppression medications, HRT and surgery. Throughout this time, I have never been provided with meaningful national data showing long-term patient outcomes, recurrence rates, effectiveness, or adverse side effects associated with these treatments.

Patients are often expected to make major medical decisions without comprehensive evidence tracking how treatments and surgery affect quality of life over time. Many women undergo repeated medications or multiple surgeries, yet outcomes are not consistently recorded or analysed to improve future care.

This petition is not anti-treatment - it is pro-evidence, informed consent and patient safety. Scotland has an opportunity to lead by creating a national database to monitor outcomes from all endometriosis treatments, surgery and HRT to improve transparency, accountability and future care in Scotland.

Annexe B: SPICe Briefing

Scottish Parliament Information Centre
Ionad Fiosrachaidh Pàrlamaid na h-Alba

Briefing for the Public Petitions Committee on petition PE2253: Create a national database to record outcomes for all endometriosis treatments, surgery and HRT, lodged by Candice McKenzie

Brief overview of issues raised by the petition

PE2253 calls on the Scottish Parliament to urge the Scottish Government to establish a mandatory national database to record and monitor real-world outcomes from endometriosis treatments, surgery, hormone therapies, and hormone replacement therapy (HRT), to improve patient safety, informed consent, clinical understanding, and accountability in endometriosis care across Scotland.

Endometriosis care in Scotland

Endometriosis is a chronic condition in which tissue similar to the lining of the womb grows elsewhere inside the body. It is thought to affect around 1 in 10 women and girls. It is not yet known what causes endometriosis, though there are a number of theories regarding its cause.

The symptoms of endometriosis can vary between affected individuals, but generally include pelvic pain, periods heavy and painful enough to disrupt daily life, pain during sex, persistent exhaustion, and fertility issues. Living with endometriosis can also carry mental, social, and financial impacts for affected women and girls, because the severe chronic pain associated with the condition can affect their mental health, cause them to take time off from work or school, impair their ability to socialise with friends and family, and disrupt sexual relationships.

Women in Scotland with suspected endometriosis wait an average of ten years and two months to receive a diagnosis. This is in part because endometriosis can currently only be diagnosed through laparoscopic surgery, in addition to social factors that may delay women seeking medical care, such as the stigma associated with periods, and the normalisation of pelvic pain for women who experience painful periods.

There is currently no cure for endometriosis. The treatment options offered to patients with endometriosis focus on reducing pain, improving quality of life, and supporting fertility for women who hope to become pregnant. The treatment offered to people with endometriosis can vary according to their individual circumstances, and the impact of endometriosis upon their daily life. NHS Scotland has developed an endometriosis pathway to guide clinical decision-making regarding endometriosis care and treatment.

Treatments may include pain relief, and hormonal medication such as the contraceptive pill to prevent the production of oestrogen, which is thought to

stimulate endometriosis. Some women may be offered gonadotropin-releasing hormone (GnRH) analogues, which also reduce the production of oestrogen. GnRH analogues place the body in a temporary menopause-like state. Hormone replacement therapy (HRT) is usually recommended alongside GnRH analogues to mitigate the side effects of the treatment.

Surgery may also be offered to some people with endometriosis. Surgery may involve excision (removal of endometriosis tissue) or ablation (destruction of endometriosis tissue using heat or lasers). Some women with more severe endometriosis may be offered more complex surgery involving organs including the bowel and bladder.

Although some women experience relief from their symptoms following endometriosis surgery, their symptoms can recur, sometimes necessitating further surgery. For other people living with endometriosis, surgery may not provide symptom relief.

Evidence regarding endometriosis treatment

NHS Scotland's endometriosis pathway is informed by the National Institute for Health and Care Excellence (NICE) guidelines concerning endometriosis treatment. NICE's guidelines are rooted in evidence-based decision-making. NICE has also published the rationale behind its decision-making process regarding endometriosis treatment.

Despite the prevalence of endometriosis, the condition remains under-researched and poorly understood. However, there are some large-scale research projects underway in Scotland, which aim to better understand endometriosis and develop more effective treatments. The University of Edinburgh's ENDO1000 project aims to collect data and biological samples from 1,000 people with endometriosis across the UK, to support research into the development of personalised care for people with endometriosis. The University of Aberdeen recently received a £2.4 million grant to trial a new individualised pain management programme for endometriosis treatment.

The petition calls for the introduction of a mandatory national database to record the outcomes of endometriosis treatment. Some data on endometriosis treatment is collected at national level from endometriosis treatment centres across the UK, including Scotland, by the British Society for Gynaecological Endoscopy (BSGE). However, the data only concerns endometriosis surgery, and is only accessible to clinicians who have access to the password-protected database. It cannot therefore be accessed by patients to aid decision-making.

There are some international examples of large-scale data sharing regarding endometriosis treatment outcomes. In Australia, the National Endometriosis Clinical and Scientific Trials (NECST) Registry collects information from people living with endometriosis to create a picture of how endometriosis affects people's daily lives. This registry is voluntary and populated by people affected by endometriosis, as opposed to a mandatory database maintained by clinicians.

In Denmark, the Danish National Patient Register holds information regarding all examinations and treatments in Danish hospitals in the last 40 years, including endometriosis treatment. However, the data is limited to hospital settings, and may

therefore only reflect the outcomes of women with more severe endometriosis requiring surgery, omitting those with mild to moderate symptoms that are managed through primary care.

In its written response to the petition, the Scottish Government stated that although it acknowledges the potential benefits of such a database for women with endometriosis, it does not consider the creation of a database to be practical or achievable. In addition to the resources required to develop and maintain the database, any necessary training and time spent inputting data would carry implications for clinical staff time. The recording of endometriosis treatment outcomes takes place across different settings in primary and secondary care, where different systems and coding are used. Collating this data into a national database would therefore necessitate the standardisation of coding across primary and secondary care in all health boards.

Scottish Government actions

The Scottish Government has stated that it is "committed to ensuring those living with endometriosis are able to access the best possible care and support." Its written response to the petition highlighted several recent actions intended to improve endometriosis care, aligned with its Women's Health Plan:

- Updating the Endometriosis Care Pathway to align with NICE guidance.
- Developing accessible information on endometriosis, including the NHS Inform Women's Health Platform and resources on treatments and self management tips for managing endometriosis pain, developed by Endometriosis UK with funding from the Scottish Government.
- Funding research projects which seek to establish more effective treatment and management options for the condition with the ultimate aim of working towards a cure for endometriosis. The written submission lists a number of examples of research projects funded by the Scottish Government.

Scottish Parliament actions

The petitioner previously submitted a similar petition in November 2025. The Session 6 Citizen Participation and Public Petitions Committee considered the petition on 21 January 2026, and decided to close it on the grounds that, with only five meetings left before the dissolution of the Parliament, the Committee would not be able to give the petition due consideration. However, the Committee encouraged the petitioner to resubmit her petition at the beginning of Session 7, and stated that in their view, the petition warranted an evidence session with the relevant Minister.

Key Organisations and relevant links

- Endometriosis UK – the UK's leading charity for people affected by endometriosis
- The Women's Health Plan: Phase Two
- The Scottish Government's endometriosis policy webpage

PPC/S7/26/6/6

Sarah Swift
Researcher
8 October 2026

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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Annexe C: Written Submissions

PE2253/A: Create a national database to record outcomes for all endometriosis treatments, surgery and HRT

Scottish Government written submission, 6 October 2026

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

The Scottish Government is supportive of initiatives that would improve women's experience of endometriosis, and their ability to make informed choices about their treatment and care.

The petition's proposal to establish a mandatory national database to record and monitor outcomes for endometriosis treatments, surgery and HRT could bring benefits for women living with endometriosis, but the Scottish Government considers there are complexities in its development that means establishing a national database is not practical or achievable at this current time.

Databases are complex structures to build and maintain and any such product would require resource expertise in specialist data handling and analytical skills to design, maintain and interrogate the data to successfully achieve the intended outcome of the petition. 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. Ongoing training would be required to ensure consistent, accurate recording of information by a workforce that will change over time. Routine quality assurance and auditing would also need to take place to monitor data quality and robustness.

Patient reporting on outcomes of treatments take place in both primary and secondary care settings, where different systems and coding are used by clinicians, which would be difficult to capture in a national database. For a national database to be routinely updated, a standardised way of coding would need to be in place across all health boards in both primary and secondary care.

NICE guidelines for the diagnosis and management of endometriosis were updated in 2024. Alongside these, NICE identified several priorities for further research. One of these relates to the effectiveness of laparoscopic interventions, and current research funded by Scottish Government will help strengthen the evidence base in this area.

What, if any, action is the Scottish Government 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?

Endometriosis remains a priority for the Scottish Government and plays a key part within the Women's Health Plan. We want all women and girls feeling informed, supported and confident in their menstrual health so that they enjoy the best possibly gynaecological health throughout their lives.

Scotland was the first country in the UK to publish a Women's Health Plan in August 2021. Phase Two of the Women's Health Plan, published in January 2026, builds on progress made to date. Through the actions in Phase One and Two, the Scottish Government is working to ensure 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 women at the centre of their care.

This includes:

- The Endometriosis Care Pathway has been fully updated in line with NICE guidance.
- Accessible information on endometriosis has been developed including the NHS Inform Women's Health Platform and resources on treatments and self-management tips for managing endometriosis pain developed by Endometriosis UK with funding from the Scottish Government.
- Endometriosis research projects have been funded by the Scottish Government which seek to establish more effective treatment and management options for the condition with the ultimate aim of working towards a cure for endometriosis. This includes research to better understand the effectiveness of some existing treatments to ensure patients receive the best possible care.

Women's Health 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 Annexe.

Through the Chief Scientist Office, we will continue to invest in health research providing funding for grants and fellowships. Alongside our Women's Health Research Fund, we have established a Women's Health Research Network for Scotland chaired by leading endometriosis expert Professor Andrew Horne.

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?

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.

Any patient who suffers side effects from taking a medicine should complete and send a "yellow card" report. Healthcare professionals who become aware of side effects in patients can also send in reports.

Women's Health Plan Team

Annexe to Scottish Government written submission, 6 October 2026

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.

PE2253/B: Create a national database to record outcomes for all endometriosis treatments, surgery and HRT

Petitioner written submission, 10 November 2026

Thank you for the opportunity to comment further on the Scottish Government's written submission dated 6 October 2026.

I welcome the Government's acknowledgement that a national database could benefit women living with endometriosis and support informed treatment decisions.

However, I am concerned that its conclusion that such a database is currently impractical or unachievable does not sufficiently explain the evidence behind that position or identify a clear alternative for addressing the gaps in treatment-outcomes data.

1. Assessing Feasibility

The Government identifies several potential barriers, including development costs, specialist staffing, clinical workload, training, data quality and inconsistent coding across primary and secondary care.

I recognise that these are legitimate considerations. However, the submission does not provide specific cost estimates, identify a completed feasibility assessment or explain whether different models of implementation have been examined.

Importantly, the Government frames the proposal as a mandatory national database. Has it considered whether alternative arrangements, including a phased introduction, a pilot programme or a more targeted approach using existing infrastructure, could achieve meaningful progress without requiring immediate implementation of a fully comprehensive system?

A minimum dataset with agreed outcome measures and recording standards may offer a practical starting point while limiting demands on clinical services.

I would welcome clarification on what assessments have informed the Government's position and whether the practical challenges identified have been evaluated against these alternative approaches.

2. Existing Systems and Opportunities

The Government identifies differences in clinical recording systems and coding as a significant obstacle.

However, these difficulties should surely be regarded as areas requiring investigation and development, rather than reasons to bring consideration of a national approach to a halt.

Has the potential to build upon or link existing NHS Scotland and Public Health Scotland information systems been formally assessed? Could consistent minimum recording standards be developed across health boards to improve the collection of endometriosis treatment information?

Recording that a woman has received a diagnosis, prescription or surgical procedure is not necessarily the same as recording what happened afterwards. The effectiveness of treatment, subsequent interventions, complications, adverse effects and longer-term outcomes require meaningful evaluation.

The Government's submission should explain how these outcomes are currently monitored and what improvements are being considered.

3. Research, Treatment and Patient Outcomes

The Government highlights its investment in endometriosis research, including ENDO1000, which aims to collect information and biological samples from 1,000 individuals over an extended period.

I welcome this research and recognise its potential contribution to improving our understanding of endometriosis and treatment outcomes. However, a research cohort and routine national treatment-outcomes monitoring serve different purposes. A research project, however valuable, does not automatically provide a comprehensive, representative picture of treatment experiences and outcomes across the wider population.

Similarly, the Government refers to the MHRA and the Yellow Card scheme. These are important components of medicine regulation and safety monitoring. However, reporting suspected adverse drug reactions does not provide the same information as systematically recording treatment effectiveness, symptom progression, quality of life, treatment discontinuation and longer-term patient outcomes.

The Government also refers to NICE guidance and research into the effectiveness of laparoscopic interventions. While this research is important, the recognised need for further evidence reinforces the importance of collecting reliable information about what happens to people following treatment.

Women with endometriosis often face particularly complex decisions regarding hormone treatments, including HRT. Endometriosis is recognised as an oestrogen dependent condition, and many women report concerns about symptom recurrence, disease progression or the need for further interventions following hormonal treatment. In my own experience, and in the experiences shared by many women within the endometriosis community, some have required additional surgery following treatment.

However, without consistent national outcome data, patients are frequently told they are simply "hormonally sensitive" rather than being able to rely on robust evidence about longer-term outcomes. This highlights the need for comprehensive monitoring so that clinicians and patients can make informed decisions based on real-world data rather than uncertainty or anecdotal experience.

I would also welcome clarification on how patient-reported outcomes and lived experiences will be incorporated into future work. Clinical records alone cannot necessarily capture the full impact of treatment on daily functioning, pain and quality of life.

4. A Clear Commitment to Progress

The Scottish Government states that endometriosis remains a priority within its Women's Health Plan. I welcome its ongoing work to improve care pathways, research and access to information.

However, improvements to care pathways and research investment do not, in themselves, resolve the need for consistent information about treatment outcomes.

If a mandatory national database is not considered achievable at present, what alternative action will the Government take? Will it commit to examining existing data infrastructure, establishing which outcomes should be recorded and identifying a realistic route towards better national monitoring?

I would also ask how progress will be evaluated and how women with lived experience will be involved in determining what information is important to collect.

Has the Scottish Government considered commissioning a formal feasibility study into the creation of a national treatment-outcomes database for endometriosis?

Conclusion

This petition is not an argument against existing treatments, surgery, hormone therapies or the professionals providing care. It is an argument for better evidence, transparency and accountability.

Women deserve to make informed decisions based on reliable information about the treatments available to them. They also deserve confidence that the effectiveness, risks and longer-term consequences of those treatments, including surgery and hormone therapies such as HRT, are being properly understood.

I recognise the financial, technical and workforce challenges identified by the Scottish Government. However, identifying these challenges should not bring the discussion to a conclusion.

I ask the Committee to seek further clarification from the Scottish Government on the evidence underpinning its position, the alternative approaches it has considered and, most importantly, what practical commitments it is prepared to make to address the gaps in endometriosis treatment-outcomes data.

We cannot improve what we do not adequately measure.

I respectfully ask the Committee to keep the petition open while seeking further clarification from the Scottish Government.