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.