

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

Scottish Government written submission, 26 November 2025

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 suppress 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.