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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

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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

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