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An t-Ionad Fiosrachaidh

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

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.

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[1] Endometriosis UK – Facts and Figures

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.

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.

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