EXECUTIVE SUMMARY - ENDOMETRIOSIS

Endometriosis occurs when tissue similar to the lining of the uterus is found in places outside the uterus. These deposits can bleed in response to hormones, causing pain and scarring in the pelvis. A delay in diagnosis is a significant issue as it can lead to prolonged suffering, ill health, and risks to fertility. Delays occur due to a perception that pelvic pain and heavy vaginal bleeding can be normal, and because healthcare professionals do not always consider the presenting symptoms to be endometriosis - there may be many symptoms, not just cyclical pain and heavy bleeding.

FOR MORE INFORMATION ON ENDOMETRIOSIS VISIT: Endometriosis UK

Endometriosis is often treated as multiple episodes of acute care, instead of on a continuum like other chronic conditions, such as diabetes or inflammatory bowel disease. This approach needs to change to enable appropriate pathways of care, holistic and medical management, discharge planning and follow-up.

IN THIS STUDY

The pathway and quality of care provided to patients aged 18 years and over with a diagnosis of endometriosis was reviewed. The sampling period of 1st February 2018 to 31st July 2020 was used and data were included from 623 clinician questionnaires, 167 organisational questionnaires and the assessment of 309 sets of case notes. In addition, a patient survey was completed by 941 respondents and a clinician survey by 137 respondents.

1. Endometriosis is a chronic condition

Unlike other chronic conditions, such as diabetes, there is no pathway for endometriosis.

36/136 **(26.5%)** patients had a **delay in initial referral to gynaecology** and in 25/36 patients this impacted on the quality of the care they received.

124/238 **(52.1%)** patients experienced **recurrence or persistence of endometriosis symptoms** following laparoscopy. 32/124 **(25.8%)** patients had a **delay in being reseen**.

2. Endometriosis has symptoms and signs that need earlier recognition for appropriate timely management

Signs and symptoms of endometriosis need to be recognised and not just seen as troublesome periods.

Presenting symptoms were most often **painful/irregular/heavy periods** or painful intercourse in 220/234 **(94.0%)** patients. But **also bowel** in 34/234 **(14.5%)** and **urinary/bladder** symptoms in 14/234 **(6.0%)** patients, or an **inability to conceive in** 12/234 **(5.1%)**.

546/941 **(58.0%)** patients surveyed **had multiple visits to the GP** before any investigations were undertaken or treatment initiated.

3. Endometriosis effects quality of life. All patients should be asked about the effect of disease on their life

Access to supportive services would enable patients with endometriosis to manage their condition.

Failure to refer to supportive services resulted in **less than best practice** for 70/309 **(22.7%)** patients.

420/941 **(44.6%)** of survey respondents stated that they were **not asked at any point about the impact of symptoms on their quality of life**.

4. Endometriosis requires holistic, joined-up, multidisciplinary care

Multidisciplinary care is essential to ensure patients with endometriosis have all their care needs met.

Only 73/167 **(43.7%)** of **hospitals reported MDT meetings** were held for patients with endometriosis.

Reviewers found that only 27/242 **(11.2%)** patients were **formally discussed in an MDT meeting** and 28/215 **(13.0%)** patients who were not discussed **should have been**.