

# FOCUS ON RESEARCH

## LONG TERM HEALTH OF WOMEN DIAGNOSED WITH ENDOMETRIOSIS: A SCOTTISH LINKAGE STUDY

### Researchers

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### Aim

Endometriosis is a common condition in women which often causes pain. It is caused by the growth of cells, similar to those lining the cavity of the uterus, in other locations, usually within the pelvis

The aim of this project was to assess long term health outcomes in women diagnosed with endometriosis in terms of risk of gynaecological operations, cancer and future pregnancy.

### Project Outline/Methodology

This study linked a number of routinely collected health records data – Scottish Morbidity Records of hospital admissions, pregnancy and neonatal records, General Register of Deaths and Cancer Registry. Women diagnosed with endometriosis from 1981 to 2009 were compared to three different groups of women without a diagnosis of endometriosis. These included those underwent diagnostic laparoscopy (key hole surgery) or laparoscopic sterilisation and healthy women from the general population.

Women who had a pregnancy following a diagnosis of endometriosis were compared to a random sample of women without endometriosis who had a pregnancy during the same time period.

### Key Results

The risk of having another gynaecological operation was significantly higher in women with endometriosis with 60% needing surgery in comparison with 51%, 36% and 17% respectively in women in the diagnostic laparoscopy, laparoscopic sterilisation and general population groups. At 1.8 years, the average time to any gynaecological surgery was much shorter in women with endometriosis when compared to the corresponding periods (4.2, 7.6 and 6.6 years respectively) in the three other groups. The risk of gynaecological (including breast) and non gynaecological cancer in women with endometriosis was comparable to the first two groups and lower than the general population.

The risk of miscarriage was 1.8 times higher and that of an ectopic pregnancy (pregnancy outside the womb) 2.7 times higher in women with endometriosis compared to other women. During pregnancy, women with endometriosis were twice more likely to have a lowlying placenta causing bleeding in pregnancy, a 40% higher risk of caesarean section and a 26% increased risk of having a premature baby.

### Conclusions

This study showed that Scottish women with endometriosis had a much higher risk of gynaecological surgery with 50% needing an operation within 2 years of diagnosis. Endometriosis does not appear to increase the risk of developing future cancer. Women with endometriosis who become pregnant have a higher risk of early pregnancy loss (miscarriage, ectopic pregnancy), bleeding during pregnancy, caesarean section and preterm birth. Thus, long term health outcomes appear to be poorer in women with endometriosis compared to those without the condition.

### What does this study add to the field?

Previous reports based on small numbers of women followed up for relatively short period of time, have shown similar results. Most lacked a definitive diagnosis of endometriosis which is only possible by means of key hole surgery (laparoscopy). This study, using routinely collected national data, had the power and sufficient length of follow up to provide a definitive answer regarding three important long - term health outcomes in women with endometriosis.

### Implications for Practice or Policy

This study has improved our knowledge of the natural history of endometriosis. The findings of this study can be used to counsel women and involve them in planning and delivering a customised care pathway. It will also help in planning specialist services and optimising strategies for the care of women diagnosed with this condition.

### Where to next?

Further research is required to study the effect of different types of endometriosis and use of hormonal treatment on future health - including, subfertility. Research is also required to establish optimal pathways for the management of these women.

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