

Partners not patients: Healthcare for endometriosis from the perspectives of women and clinicians

The researchers

This research project was conducted by Dr Kate Young to fulfil the requirements of a PhD. She was supervised by Dr Maggie Kirkman and Prof Jane Fisher in the Global and Women's Health Unit, Public Health and Preventive Medicine, Monash University.

The study

Before this research, there was little on endometriosis that sought the perspectives and experiences of the women who live with the condition. There had also been no research about how Australian doctors provide care to women with endometriosis. Kate interviewed 26 women from diverse backgrounds about their experiences of endometriosis and 12 doctors (GPs and gynaecologists) about their experiences of providing care to women with endometriosis. Kate also conducted an analysis of an Australian fertility survey to compare the experiences of women with and without endometriosis.

Thank you to the women and clinicians who generously gave their time to share their experiences of, and perspectives on, endometriosis.

What we found

We published our results in medical and health journals. Below are the titles of these papers which are linked to the online version. Kate also produced or facilitated at least one media article for each paper so that the results could be more widely distributed. A sample is listed for each paper below.

- [Women's experiences of endometriosis: A systematic review and synthesis of qualitative research](#)
 - Media article: [Women with endometriosis need support, not judgement](#)
- ["Do mad people get endo or does endo make you mad?": Clinicians' discursive constructions of Medicine and women with endometriosis](#)
 - Media article: [Endometriosis, women's health and the 'hysteria myth'](#)
- [Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis](#)
 - Media article: [This is what women with endometriosis want from their doctors](#)
- [Clinicians' perceptions of women's experiences of endometriosis and of psychosocial care for endometriosis](#)
 - Media article: [Do mad people get endometriosis or does endo make you mad?'](#)
- [Endometriosis and fertility: Women's accounts of healthcare](#)
 - Media article: [With endometriosis, shouldn't 'let's get you well' come before 'let's get you pregnant'?](#)
- [Fertility experiences in women reporting endometriosis: Findings from the Understanding Fertility Management in Contemporary Australia survey](#)
 - Media article: [Infertility is an issue for some women with endometriosis. But it's not the whole story](#)

Where to now?

Our research identified a need for doctors to be better supported to provide women with quality care for endometriosis, particularly for women who had tried available treatment options with little symptom relief. We also identified a need for more research into the reproductive healthcare needs of women with endometriosis beyond the current focus on infertility. We are seeking funding to address these gaps to foster healthcare that meets women's diverse needs.

