

Establishment of the National Endometriosis Clinical and Scientific Trials (NECST) Registry to study the life course and impact on quality of life of people living with endometriosis.

ACTRN12622000987763

Status	RECRUITING
Sponsor	UNSW
Enrollment	5,000 participants

Plain Language Summary

Endometriosis is a condition where tissue similar to the lining of the uterus grows outside of it — on the ovaries, fallopian tubes, or elsewhere in the pelvis. It can cause chronic pelvic pain, painful periods, pain during sex, and fertility problems. Shockingly, it can take 7–12 years from first symptoms to a confirmed diagnosis, largely because of how little is understood about the condition's causes and progression.

The NECST Registry is a national Australian initiative to change this by collecting detailed health information from people with endometriosis or related conditions like adenomyosis over their lifetime. This long-term data will help researchers understand how endometriosis develops, find better diagnostic tools, and improve treatment options for the millions of Australians affected.

You may be eligible if you are an Australian resident, are 18 or older, speak English, and either have surgically confirmed endometriosis or adenomyosis, or experience symptoms that may be related — such as persistent pelvic pain, heavy periods, pain with bowel movements or urination, pain during sex, or difficulty falling pregnant. Participating involves completing surveys about your health and experiences.

Key Eligibility Criteria

Inclusion (10)

- Have had surgery which has confirmed that you have endometriosis or adenomyosis
- Have any of the below symptoms that might be caused by endometriosis:
 - persistent pelvic pains
 - problems with falling pregnant
 - excessive menstrual bleeding or bleeding between periods

... and 5 more (see full listing online)

Exclusion (4)

- Women unable to provide informed consent;
- Females aged under 18 years of age;
- Women who are not resident in Australia or planning to not reside in Australia for the foreseeable future;
- Women with insufficient English language ability to give informed consent and complete the baseline survey instruments (at this stage consent materials and survey modules are only available in English).

Locations (21 total)

Royal Hospital for Women - Randwick, ACT,NSW,QLD,SA,WA,VIC, Australia
Prince of Wales Private Hospital - Randwick, ACT,NSW,QLD,SA,WA,VIC, Australia
St George Hospital - Kogarah, ACT,NSW,QLD,SA,WA,VIC, Australia

... and 18 more locations

<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=ACTRN12622000987763>

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