



Australian Government
Department of Health and Aged Care

Endometriosis Progress Report

2024 Update



The Australian Government is taking active steps to address the significant burden that endometriosis places on Australians. Since the release of our National Action Plan for Endometriosis in July 2018, we have committed \$87.2 million for a suite of initiatives aimed at improving endometriosis and pelvic pain diagnosis, primary care support and helping more individuals find appropriate care and better manage the impact of endometriosis and pelvic pain.

This includes:

- clinical management and care
- research
- awareness and education

We are working with stakeholders throughout the health system, medical researchers, peak bodies and endometriosis and pelvic pain support groups on a coordinated approach to improve awareness and understanding of endometriosis, and to develop better treatment options and speed up diagnosis and primary care support. These efforts will help more people find appropriate care and better manage the impact of endometriosis and pelvic pain in Australia.

Clinical management and care

The health sector is key to improving outcomes for people with endometriosis. We are working with the sector to improve access to services that are appropriate and accessible. This includes the current 2022-23 endometriosis support Budget measures:

- \$25.5 million for access to a new Medicare funded [magnetic resonance imaging \(MRI\)](#) scan to assist in the investigation of infertility for those with severe endometriosis and other conditions (implemented 1 November 2022).
- \$17.4 million to support [22 specialised Endometriosis and Pelvic Pain GP clinics](#) across Australia, providing multi-disciplinary care with a focus on improving diagnostic delay and to promote early access to intervention, care and treatment options for endometriosis and pelvic pain (from 2022-23 to 2025-26).
- \$5.1 million for the development of an Endometriosis Management Plan to support patients in primary care, including in the Endometriosis and Pelvic Pain clinics (from 2022-23 to 2025-26).
- \$0.8 million for the development and promotion of an Endometriosis Living Guideline to support new and ongoing research into the diagnosis and management of endometriosis (including pain management) (from 2022-23 to 2024-25).
- \$0.3 million to improve the utilisation of existing Medicare Benefits Schedule and Pharmaceutical Benefits Scheme items through ongoing review and promotion of available treatments for endometriosis to ensure clinicians and those suffering from pelvic pain and endometriosis are aware of available Government subsidised services and medicines.

Research

Australia is well placed to lead and develop research on endometriosis. The Government has invested in research that will pave the way for prevention and the development of a cure.

From its inception in 2015 to 31 January 2024, the Medical Research Future Fund (MRFF) has invested \$19.11 million in 11 grants with a focus on endometriosis research. Some examples of grants awarded include:

- \$9.59 million through the MRFF 2019 Endometriosis Research grant opportunity for 5 research projects to improve diagnosis, treatment and understanding of endometriosis. These are:
 - \$3.93 million to the University of Melbourne to improve diagnosis and treatment of endometriosis,
 - \$1.96 million to Murdoch Children’s Research Institute for the ‘Longitudinal Study of Teenagers with Endometriosis, Period and Pelvic Pain in Australia’ (LongSTEPPP study), to identify early risk factors, educational and management strategies that will lead to optimal health outcomes and appropriate health utilisation,
 - \$1.86 million to the University of Queensland for the ‘Genetic variants, Early Life exposures, and Longitudinal Endometriosis Symptoms study’ (GELLES study).
 - \$0.95 million to Monash University for a randomized controlled study examining the efficacy of the low FODMAP diet for the relief of gastrointestinal symptoms in endometriosis, and
 - \$0.89 million to Deakin University for a randomized controlled trial comparing yoga, cognitive therapy and education to improve quality of life and reduce healthcare costs in endometriosis.
- \$2.50 million through the MRFF 2018 *Accelerated Research – Endometriosis* grant opportunity to Jean Hailes for Women’s Health to establish the ‘National Endometriosis Clinical and Scientific Trials Network’ (NECST Network), for patients to take part in a coordinated national research platform.
- \$1.99 million through the MRFF 2020 *Primary Healthcare Research Data Infrastructure* grant opportunity to the University of Adelaide for the Imagendo study, diagnosing endometriosis with imaging and artificial intelligence (AI).
- \$0.93 through the MRFF 2021 *Frontier Health and Medical Research* grant opportunity to the University of Queensland for ‘Earlier Diagnosis and Personalised Treatments for Endometriosis’ (EndoAIMM).
- \$1.94 million through the MRFF 2020 *Clinician Researchers: Applied Research In Health* grant opportunity to the University Of New South Wales for ‘The Australian Endometriosis Clinicians Collaborative (AECC)’.

- \$0.69 million through the MRFF 2021 *Research Data Infrastructure* grant opportunity to the University of New South Wales for 'EndoLinked: Identifying fertility outcomes for women with endometriosis'.
- \$1.47 million through the MRFF 2021 *Clinical Trials Activity* to Deakin University for 'CoDeEndo: Co-Designing, Evaluating, and Implementing Supportive Care for Endometriosis'.

Further, between 2014 and 2023, the National Health and Medical Research Council has funded 20 research projects relevant to endometriosis. Some examples of research projects awarded include:

- \$2.14 million awarded to Monash University for the 'Translating Endometrial Stem/Progenitor Cell Discoveries to Transform Women's and Girls' Gynaecological Health Outcomes' project which aims to reveal the role of endometrial stem cells in endometriosis and to examine how endometrial mesenchymal stem cells can be used as a therapy for pelvic organ prolapse.
- \$1.22 million awarded to University of Melbourne for the 'Identification and function of genes that increase risk for endometriosis' project which aims to investigate the functional roles that endometriosis susceptibility genes play within the uterus, with the goal of identifying new treatments for endometriosis.
- \$1.01 million awarded to University of Queensland for the 'Identifying endometriosis risk and disease variability by mapping endometrial stem cell maturation' project which aims to identify factors that cause altered differentiation and the biological signatures that result to improve treatment.
- \$0.57 million awarded to Flinders University for the 'Decoding the pathophysiology of chronic pelvic pain associated with endometriosis and related visceral comorbidities' project which aims to identify the molecular entities/mechanisms responsible for pain detection and transmission in endometriosis, to provide novel therapeutics strategies and ultimately improve Endo patient's quality of life.
- \$1.27 million awarded to Royal Melbourne Institute of Technology University for the 'A new way to see endometriosis' project which aims to study the fundamental biology and function of uterine cells and exploring new diagnostic and therapeutic options for endometriosis.

In addition:

- \$5.1 million to support to the NECST Network to continue growing research capacity and address research gaps (from 2022-23 to 2025-26).
- \$1.4 million for the continued support for the EndoZone digital platform to provide consumer access to evidence-based information (from 2022-23 to 2024-25).

Awareness and education

Greater awareness, acknowledgement and education will improve responses to endometriosis. The Government continues to invest in targeted education initiatives and campaigns to improve understanding for patients, health and education professionals, and the community.

Our commitment includes:

- \$2 million for Increasing Awareness of Endometriosis Amongst Priority Populations, implementing a Mentor Program to support those newly diagnosed with endometriosis and implementing a Workplace Assistance Program to support employees and employers navigate discussions in the workplace (from 2023-24 to 2025-26)
- \$5 million for the Periods, Pain and Endometriosis Program (PPEP-Talk) program continuation and national expansion to schools. PPEP-Talk is a one-hour session to high school students to learn how to recognise when menstruation symptoms are not normal and when to go for advice and help (from 2021-22 to 2024-25).

Endometriosis Advisory Group

The Endometriosis Advisory Group (EAG) is appointed by the Department of Health and Aged Care to provide advice and guidance to the Department on issues relating to implementation of the National Action Plan for Endometriosis. The EAG undertakes to:

- Prioritise proposed actions outlined in the Action Plan, including providing advice on the potential costs, cost-effectiveness, barriers to, enablers for, and probable timeframes associated with the proposed actions.
- Provide advice on the ways in which prioritised actions may be shaped, developed and implemented, including identifying the sector area responsible for driving implementation of each action, and who the key implementation partners are.

National Action Plan for Endometriosis

The National Action Plan for Endometriosis (NAPE) was developed from partnerships between government, endometriosis experts, and endometriosis patient and community organisations. It identified a need for raised community and healthcare provider awareness to improve visibility and diagnosis of endometriosis. Action and priority were across three key areas: i) awareness and education, ii) clinical management and care, and iii) research.

The NAPE has six criteria, these are:

1. development of a nationally endorsed endometriosis Living Guidelines;
2. provision of improved access to appropriate health care, including assessment, diagnosis, pain management, psychosocial support, and specialist services;
3. implementation, and embedding, of a school menstrual education program, with increase in students' knowledge and awareness;
4. demonstration of an increase in the base-level understanding of endometriosis among GPs, other health care professionals, employers and the community;
5. availability of optimal care pathways, from first consultation to surgical intervention and post-operative care; and
6. demonstration of significant expansion of the domestic research program, with a view of meeting international endometriosis research priorities.

For all the criteria above, the department has commenced all the programs and activities to meet the objectives of the NAPE. The next phase of the NAPE is to complete these objectives and evaluate their effectiveness.