



**Australian Government**

**Department of Health**

# NATIONAL ACTION PLAN FOR ENDOMETRIOSIS – REVISED DRAFT

The Department of Health

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## ABOUT THE PLAN

There is growing recognition within Australia of the need for improved awareness, education, diagnosis, treatment of, and research into, endometriosis and pelvic pain. This National Action Plan for Endometriosis emerges from the combined efforts of patients, advocacy groups, clinicians, researchers and parliamentarians to have endometriosis acknowledged as a substantial health burden in Australia.

The Turnbull Government announced the development of the Action Plan in December 2017. This is the first National Action Plan for Endometriosis. It provides a platform for improving the awareness, understanding, treatment of, and research into, endometriosis and pelvic pain in Australia.

Investment into endometriosis awareness, education, diagnosis, treatment of, and research will benefit women and girls affected by endometriosis and chronic pelvic pain, with earlier diagnosis and intervention, broader multi-disciplinary treatment options and clear care management pathways made possible. Investment could also benefit the Australian community, with a reduction in the overall burden of disease, through lower healthcare costs and absenteeism rates, and an increase in social and economic participation made possible.

With increased funding directed towards research, both prevention of and a cure for endometriosis may be achievable - the aspirational goal of this Plan.

The Action Plan is aligned to the goals of the National Strategic Framework for Chronic Conditions, which was published by the Australian Health Ministers' Advisory Council (AHMAC) in 2017. It shares the aim that all Australians live healthier lives through effective prevention (where possible), early intervention and management of chronic conditions. The Action Plan also shares many of the underlying principles of the Framework, and like the Framework, builds on existing work and is designed as a tool to enhance activities already underway and to guide the development of new and innovative policies and approaches.

This National Action Plan is one of the first steps for Australia's renewed action on endometriosis.

## Acknowledgements

Many organisations and individuals have contributed to the development of this first National Action Plan for Endometriosis. In particular, we would like to thank the following:

ACE - Australian Coalition for Endometriosis (comprising the following organisations)

Canberra Endometriosis Network  
EndoActive  
Endometriosis Australia  
Pelvic Pain Foundation of Australia  
Qendo – Queensland Endometriosis Association  
Australian Gynaecological Endoscopy and Surgery Society Limited  
Australian Longitudinal Study on Women's Health  
Canberra Endometriosis Centre  
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Mercy Health  
Monash University  
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Nicolle Flint MP  
The Hon Catherine King MP  
Nola Marino MP  
Maria Vamvakinou MP  
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Robinson Research Institute  
The Royal Children's Hospital Melbourne  
The Royal Women's Hospital Victoria Australia  
The University of Adelaide  
The University of Melbourne  
The University of Queensland  
University of New South Wales  
WHoA! – Women's Health of Australia  
World Endometriosis Society

# CONTENTS

About the Plan.....	ii
Acknowledgements.....	iii
Why endometriosis matters .....	1
Call for action .....	2
Foundation for action .....	4
What we want to achieve .....	7
Partnerships.....	8
Priority areas .....	9
Priority area 1 – Awareness and education .....	10
Priority area 2 – Clinical management and care .....	12
Priority area 3 – Research .....	14
Achieving progress .....	16
Next steps .....	17
Appendix A Framework for action .....	18
Priority area 1 – Awareness and education .....	18
Priority area 2 – Clinical management and care .....	21
Priority area 3 – Research .....	25
Appendix B Implementation partners .....	27
Appendix C References .....	29

## WHY ENDOMETRIOSIS MATTERS

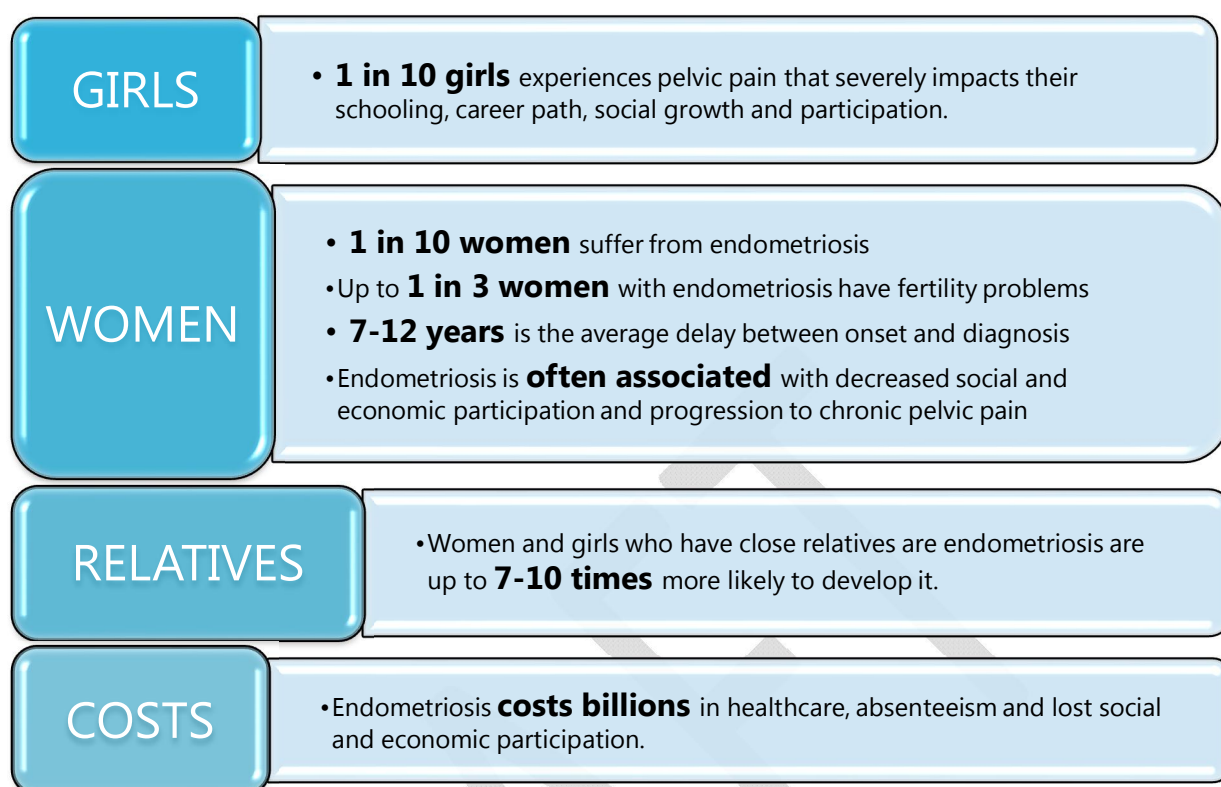
Endometriosis is a common yet commonly under-recognised chronic disease. Endometriosis occurs when cells similar to those that line a woman's uterus grow in other parts of her body, usually around the pelvis. Although many people will have endometriosis effectively managed, in many cases it can lead to debilitating, chronic pain, recurrence and compromised fertility. It can also significantly impact the social and economic participation and psychosocial health of those affected.<sup>1,2,3</sup>

It is estimated that more than 700,000 Australian women and girls are living with endometriosis; however, delays in diagnosis and a lack of definitive research on the domestic burden of disease suggest the number could be far higher.<sup>4</sup> Some research indicates the condition is more common than breast cancer, prostate cancer, and diabetes.<sup>5</sup> It can affect all women and girls, regardless of age, background or lifestyle.

The majority of Australians will know at least one person with endometriosis. Endometriosis has been historically under-recognised amongst both the medical community and the public and subsequently under-diagnosed. The delay between onset and diagnosis is, on average, between seven and twelve years.<sup>6,7</sup> This is influenced by the fact that an invasive operation is required for formal diagnosis, but also informed by stigma, as well as low education or miseducation about menstrual health.<sup>8</sup> This means that many women and girls living with endometriosis and pelvic pain are not receiving adequate treatment and management until they have had the condition for many years.

The causes of endometriosis remain unclear. It is likely that there is no single cause, and that genetic, biological and environmental factors may influence the condition.<sup>9</sup> Although treatments are available, they are not always effective. There is currently no cure for endometriosis, with symptom recurrence following medical or surgical treatments common. However, it is recognised that early assessment and intervention can lead to better long-term management, including lessening the impact of symptoms and improving quality of life, helping women and girls affected by endometriosis to live normal healthy lives.<sup>10</sup>

Figure 1: Snapshot of the impact of endometriosis in Australia<sup>11,12,13,14</sup>



## CALL FOR ACTION

It is evident that endometriosis can have a profound impact on women and girls, as well as their families and society as a whole - it is a significant issue throughout the world, with approximately 176 million women and girls suffering with endometriosis.<sup>15</sup> There is significant frustration with the under-recognition of endometriosis, and the subsequent delays from onset to diagnosis and treatment. At home and internationally, there is a pressing need to strengthen the response to the condition and to improve the quality of life for those affected.<sup>16</sup>

Given there has been little attention directed towards endometriosis to date, there is a need for significant improvements in outcomes for women and girls with this condition, with earlier diagnosis and intervention, broader multi-disciplinary treatment options and clear care management pathways possible.

Specifically, there is a need for:

### Public awareness and education

- Timely education and increased awareness for multiple groups, spanning patients, health professionals and the Australian public.
- Stronger appreciation and understanding of endometriosis as a complex chronic condition, and the psychological and social effects of endometriosis, as well as communication regarding its detrimental effects on social and economic participation.
- Leadership from schools, employers to recognise and adapt to specific challenges facing women with endometriosis and chronic pelvic pain, enabling social and economic participation.

### Access to individual information and support

- Greater clarity about the patient care pathway and where women, girls, and their support networks can seek help.

- Better-informed, earlier access to detection, intervention, management and care.
- Improved integration between services at each stage of the care pathway, to support the patient journey and streamline referral between multidisciplinary services.

#### **Services that are appropriate, available and accessible**

- Improved accessibility for people in rural and regional areas, as well as Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities and disadvantaged groups.
- Evidence-based clinical care standards and an effective accreditation process for clinicians, to promote diagnostic and treatment excellence and reduce the need for repeated surgical intervention.
- Improved, comprehensive management for complex pain, to minimise the daily impact on patients and their social, academic and professional capability.

#### **Research relevant to need**

- Support for further research to address a limited data base in Australia, and to capitalise on Australia's strong research capability to pursue international research goals.



There is a long way to go to improve outcomes for women and girls living with endometriosis and chronic pelvic pain in Australia. Indeed, Australian women have spoken powerfully about the need for action.

A small selection of the patient experiences that have been raised by Members of Parliament, voiced during the launch of the Parliamentary Friends of Endometriosis Awareness, and quoted the Australian media are illustrated in Figure 2.

Figure 2: Quotes from patients with endometriosis in Australia



# FOUNDATION FOR ACTION

## The Australian context

Despite the need for improvement, there are also multiple positives to build upon in this National Action Plan. Australia's existing health, community and research landscape provides a strong foundation for action on endometriosis and chronic pelvic pain.

Centrally, this is due to an existing, comprehensive health system with widespread, safe, and generally subsidised access to care. Strong infrastructure is supported by highly specialised expertise in endometriosis research and laparoscopic surgery, a significant range of existing online support tools and information resources and published materials, as well as goodwill and willingness for collaboration among diverse members of the endometriosis community.

This enabling environment is illustrated in Figure 3.

Figure 3: Enablers to support action in the Australian context



## International approach

Internationally, work is being undertaken to improve awareness, understanding and treatment of endometriosis. A global consortium of investigators in endometriosis have recently published their recommendations for research priorities for endometriosis,<sup>17</sup> and the Endometriosis Priority Setting Partnership (PSP) was formed with the objective of identifying the key questions about endometriosis that were most important to both women and girls who have endometriosis and healthcare practitioners involved in their care.<sup>18</sup> Following extensive consultation, the PSP agreed the top ten endometriosis research priorities in the UK and Ireland. These ten priorities are intended to ensure that future research funding and activities focus on questions that are important to women with endometriosis and to health-care practitioners. These priorities, outlined in Figure 3 below, are also relevant in the Australian setting.

Figure 4: Top ten research priorities for endometriosis in the UK and Ireland

1. Can a cure be developed for endometriosis?
2. What causes endometriosis?
3. What are the most effective ways of educating health-care professionals throughout the health-care system resulting in reduced time to diagnosis and improved treatment and care of women with endometriosis?
4. Is it possible to develop a non-invasive screening tool to aid the diagnosis of endometriosis?
5. What are the most effective ways of maximising and/or maintaining fertility in women with confirmed or suspected endometriosis?
6. How can the diagnosis of endometriosis be improved?
7. What is the most effective way of managing the emotional and/or psychological and/or fatigue impact of living with endometriosis (including medical, non-medical, and self-management methods)?
8. What are the outcomes and/or success rates for surgical or medical treatments that aim to cure or treat endometriosis, rather than manage it?
9. What is the most effective way of stopping endometriosis progressing and/or spreading to other organs (eg, after surgery)?
10. What are the most effective non-surgical ways of managing endometriosis-related pain and/or symptoms (medical/nonmedical)?

The National Institute for Health and Care Excellence (NICE) issued a new guideline on endometriosis in September 2017. The guideline, *Endometriosis: diagnosis and management*, aims to raise awareness of the symptoms of endometriosis, and to provide clear advice on what action to take when women with signs and symptoms first present in healthcare settings.<sup>19</sup> It also provides advice on the range of treatments and care pathways, they can be used by both clinicians to guide treatment options and patients to understand what to expect with the treatment and management of endometriosis.

# WHAT WE WANT TO ACHIEVE

The overall goal of the first National Action Plan for Endometriosis is:

**A tangible improvement in the quality of life for women and girls living with endometriosis, including a reduction in the impact and burden of disease at individual and population levels.**

## Supporting objectives

Figure outlines the eight supporting objectives that will enable the achievement of the goal. Each supporting objective relates directly to one of the focus areas of the National Action Plan.

Figure 5: Objectives of the first National Action Plan for Endometriosis

Awareness and education	1	Improved public understanding through targeted education initiatives and visible, widespread, public awareness campaigns and with particular regard to vulnerable and at-risk population groups.
	2	Patients are well-informed, active decision makers and participants in their own healthcare with streamlined access to a broad range of resources, self-education and self-management tools.
	3	Healthcare professionals, educators and employers take women's pain seriously and treat all patients with endometriosis with dignity and respect.
Clinical management and care	4	Early access to endometriosis-specific education, intervention, diagnosis and treatment options reduces delays at all stages of the care pathway.
	5	Affordable and accessible care options for all relevant patients, including vulnerable population groups, with nationally consistent clinical care standards and pathways support strong clinical delivery.
	6	The gap in quality of life between patients with endometriosis and their peers continues to narrow.
Research	7	Patients benefit from greater understanding of the nature of endometriosis and have access to simpler and less invasive diagnostic tests and treatment options.
	8	Research findings are translated and implemented to achieve real-world outcomes, and there is continuing progress towards the development of a possible cure.

## PARTNERSHIPS

To improve the experiences of and outcomes for women and girls with endometriosis and pelvic pain, collaborative and continued effort is required across multiple domains.

A strong partnership between government, patients, advocates, healthcare professionals and industry is necessary to implement the actions identified in this National Action Plan and to ensure their success. Concerted development and implementation of these actions has the potential to markedly improve outcomes for patients with endometriosis.

To meaningfully improve outcomes for patients with endometriosis, there is a need for collaborative action between multiple partners. There are various organisations and sectors involved in the national response to endometriosis. This includes schools and hospitals, overseen by the state and territory governments, working in unison with primary care service providers, who fall within the Commonwealth's area of responsibility.

Collaborative action also needs to involve representative and industry bodies working independently – but alongside – government-led institutions. The relevant organisations and sectors vary between actions, but there is a need for partnership across all focus areas and priorities.

It is proposed that the Framework for Action, provided at Appendix A, is used to identify each sector area with key responsibility for driving the collaborative effort required to achieve each action.

A detailed list of key partners and priority area-specific partners is also provided at Appendix B.



## PRIORITY AREAS

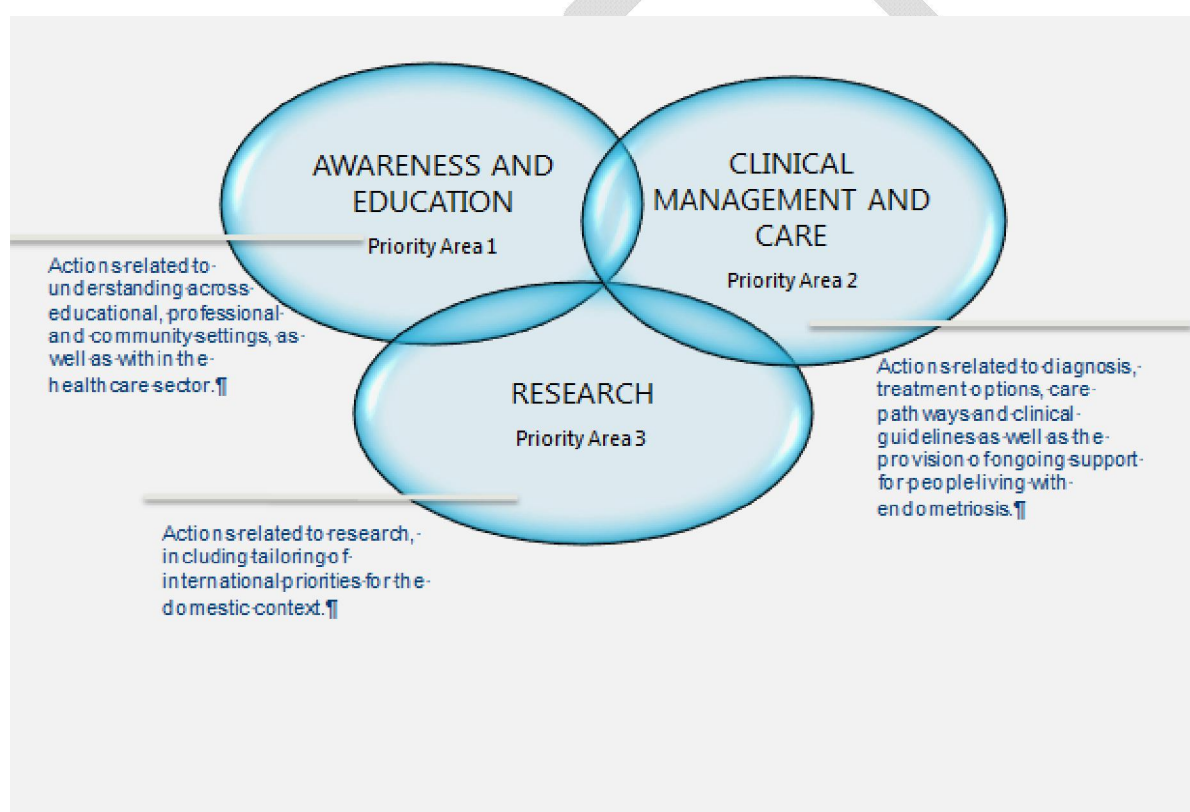
There are three priority areas set out the actions that will deliver a multipronged approach to endometriosis in Australia. Each of these priority areas contribute towards the overall goal and objectives of the National Action Plan.

The three priority areas are:

1. Awareness and education
2. Clinical management and care
3. Research

Each priority will require the cooperation of multiple parties, and attention must be paid to all three in order to achieve real progress and achieve holistic reductions in the impact and burden of disease. The integration of the priority areas is modelled in Figure .

Figure 6: Key priority areas for the Action Plan



## Priority area 1 – Awareness and education

Stronger awareness, recognition, acknowledgment and education about endometriosis are the bedrock of an improved response. Raising awareness is the first step to reducing diagnostic delay. Education, particularly in younger age groups, is fundamental for breaking the cycle of under-recognition and diagnostic delay.

This is the first priority area of the National Action Plan, which acknowledges the need to improve understanding and impact of the condition among patients, health and education professionals, the broader health sector, and the Australian community generally.

### What will be different?

The profile of endometriosis as a chronic condition will be raised, leading to an informed and accurate understanding of endometriosis by individuals, education and health professionals and the community more broadly. This will enable early recognition of symptoms, greater awareness of treatment options and understanding of the impact of the condition.

Women and girls who are at-risk or affected by endometriosis will be more empowered and active decision-makers and participants in their healthcare, supported by well-informed and respectful interactions with education and health professionals and the community.

### Priorities and actions

There are four key areas for awareness and education.

#### ① **Develop widespread, visible and context-specific community awareness campaigns delivered through multiple channels.**

##### 1.1

Develop, promote and deliver community awareness campaigns, delivered across multiple platforms, to improve the visibility of endometriosis in public life, and to ensure that endometriosis is a widely recognised chronic condition.

##### 1.2

Support the development of endometriosis-specific media and awareness materials that are tailored for Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups, and for rural and regional contexts.

##### 1.3

Develop workplace-specific materials to educate employers on the prevalence and impact of endometriosis, to enable employers and workplace human resources departments to support employees with endometriosis in a professional setting.

#### ② **Promote early education on women's health, delivered in school settings, and provided for all genders.**

**2.1** Update secondary school puberty and sexual health curriculums to include a menstrual education program resource, delivered by specially qualified personnel, to educate older students about menstrual health, the symptoms of endometriosis and related conditions. Promote access to resources for students and parents to learn more about menstrual health.

**2.2** Equip primary and secondary school educators, as well as physical and mental healthcare staff in these environments, to recognise the symptoms of endometriosis and provide resources, guidance and support to students.

**2.3** Acknowledge cultural barriers and develop education programs sensitive to the expectations of different demographic groups. Deliver endometriosis education and develop resources in multiple languages, accessible to people with varying levels of literacy and from different cultural backgrounds.

### **3 Improve access to information, self-education and self-management tools for women living with endometriosis at all stages of their journey.**

**3.1** Develop and publish an agreed clear flow diagram to map the pathway for women and girls with endometriosis or pelvic pain through the healthcare system, from first consultation through to medical intervention, to inform and enable patients to be active decision-makers and participants at each stage of care.

**3.2** Develop and promote a resource kit for women and girls newly diagnosed with endometriosis to provide general information about the condition and inform patients about where to find further resources and access support and treatment services. The kit should be provided freely and be available in both physical and discrete digital formats.

**3.3** Support the development of interactive tools (phone-based applications, web-based diagnostic tools and symptom checkers) to increase patient health literacy and promote proactive health-seeking behaviour.

**3.4** Promote existing and emerging information sources that acknowledge cultural differences around discussion of women's health and menstruation and ensure these can be accessed discreetly online through multiple sources.

### **4 Improve awareness and understanding of endometriosis among health professionals working at every stage in the clinical pathway.**

**4.1** Provide general practitioners (GPs) with concise educational materials on the prevalence, symptoms and treatment options for endometriosis, both for their own professional development and for distribution to patients. Ensure that GPs are encouraged to refer patients with pelvic pain symptoms through the appropriate care pathways.

**4.2** Educate ultrasound technicians, ultrasound specialists, radiologists and physiotherapists on the symptoms of endometriosis and enable them to assess and identify endometriosis symptoms as part of routine services for pelvic pain or related conditions.

**4.3** Educate clinicians, allied health professionals and others involved in endometriosis care on the prevalence, symptoms and available pathways for treatment and embed pain management guidance into educational programs.

**4.4** Update teaching and training standards to include endometriosis-specific education and include learning modules on endometriosis in training for all relevant specialities, across tertiary and vocational medical training programs.

**4.5** Facilitate advanced training for interested health professionals to provide an advanced level of expertise in endometriosis and pelvic pain diagnosis, treatment and management.



## Priority area 2 – Clinical management and care

Clinical management and care is the second priority area of the Action Plan. This section emphasises the pivotal role of the health sector in the combined effort to improve outcomes for patients with endometriosis.

Health professionals have roles connecting and providing services to patients at all stages of their care pathway and at any point of disease progression. They are a key audience for this National Action Plan, as are the professional, educational and industry bodies that represent them.

### What will be different?

Affordable and consistent healthcare options available nationally to support timely and effective access to endometriosis diagnosis, management and care, improving day-to-day and long-term health outcomes for all patients with care for vulnerable population groups and chronic care needs meeting standards and guidelines for all.

### Priorities and actions

There are five key areas for clinical management and care.

#### 1 **Ensure endometriosis is recognised as a significant health issue by all health practitioners, acknowledging its physical, psychological and social impacts.**

**1.1** Inform and educate health professionals about the psychological and social impacts that chronic pain and under-recognition of endometriosis has on women and girls living with the condition, and ensure access to appropriate resources, social and psychological support mechanisms, and holistic care.

**1.2** Inform and educate health professionals about the potential long-term impacts on fertility and provide support to health professionals to encourage patients with endometriosis to consider fertility and future options.

#### 2 **Develop clinical guidelines and clinical care standards to promote integrative care for all stages of the care pathway.**

**2.1** Revise, adapt and incorporate existing, international clinical guidelines on endometriosis to develop authoritative clinical guidelines and clinical care standards for health services and health practitioners throughout Australia.

**2.2** Define and document ideal evidence-based patient pathways from self-information, GP consultation through to senior specialist care, providing as a national clinical resource to guide referral and progressive movement of patients through the care system.

**2.3** Establish clear models of care (MOC) for self-management, medical management and/or surgical management of endometriosis. Develop clear clinical and plain English resources to outline best practice MOC and distribute to healthcare professionals as well as patients.

**2.4** Consider routes to develop surgical accreditation standards and assessment processes for laparoscopic surgeons, to improve the quality of laparoscopic surgery throughout the country and minimise the need for repeated invasive surgery for endometriosis.

#### 3 **Target diagnostic delay and promote early access to intervention, care, and treatment options for women and girls.**

**3.1** Devise and promote a simple, standardised and easily accessible tool to aid or precede diagnosis, that can be completed by women with potential symptoms of endometriosis prior to a GP appointment, to encourage early action and intervention.

**3.2** Clearly identify criteria to determine when follow-up interventions are needed for formal diagnosis or treatment, in order to improve triage processes for multidisciplinary endometriosis care.

**3.3** Create and support informal educational, advocacy and support networks, providing information on available clinical services and helping patients navigate the system.

#### **4 Improve the affordability, accessibility and national consistency of management and care options for women throughout Australia.**

- 4.1** Develop and deliver a national rollout of the clinical guidelines and clinical care standards, to ensure that services are provided at a uniform baseline quality across the country.
- 4.2** Support the dissemination of best practice information and approaches throughout services in Australia.
- 4.3** Develop a phone-based application for clinicians to support the observation of symptoms of endometriosis and clarify 'next steps' for referral at any stage of the care pathway.
- 4.4** Ensure no specific populations or demographic groups 'fall through the gaps' by integrating clinical guidance on endometriosis into guidelines for services targeted towards vulnerable and at-risk groups.
- 4.5** Develop messaging to patients with endometriosis to reassure them that any conversations with their GP or healthcare provider regarding their sexual or reproductive health is confidential.
- 4.6** Reduce barriers to assessment and treatment by pursuing options to reduce the cost of consultations and medications for women and girls with endometriosis and pelvic pain.

#### **5 Narrow the gap in quality of life between patients and their peers.**

- 5.1** Improve access to, and encourage patients to consult with, hormone-based pain management specialists to reduce day-to-day impact on personal life, contribution and social and economic participation, leading to improved outcomes.
- 5.2** Use clinical care standards to optimise outcomes for women and girls with endometriosis, ensuring the right care at the right time in the right place.
- 5.3** Promote strong multidisciplinary teams by strengthening clinical pathways between specialists involved in the daily management of endometriosis symptoms.

## Priority area 3 – Research

Due to the strength, collaborative will and specialised knowledge of its research community, Australia is well placed to lead and develop endometriosis research on an international scale. Accordingly, research is the third priority area of the National Action Plan.

An initial Commonwealth investment of \$2.5 million through the Medical Research Future Fund to support research into endometriosis, including funding a clinical trials network, NHMRC clinical or research fellowships and a small grants programme for medical research.<sup>20</sup> The funding will support the following research priorities and actions, identified by contributors to the National Action Plan.

### What will be different?

The research opportunities offered by the National Health and Medical Research Committee and, in particular, the funds made available through the Medical Research Future Fund will offer significant opportunities to make immediate and longer-term improvements in health outcomes for people living with endometriosis, both in Australia and internationally. Specifically, research will enable a more accurate quantification of the burden of disease and further investigation of its epidemiological nature (including its causes and the potential for a cure) and will be supported by discerning, effective use of clinical trials.

### Priorities and actions

There are three key areas for research.

#### ① **Build a collaborative environment that enables world-leading research on endometriosis.**

- 1.1 Develop a national Clinical Trials Network that coordinates support for research organisations to conduct clinical trials for endometriosis treatments and services.
- 1.2 Develop an Australian Research Collaboration Framework to support coordinated patient recruitment, consistent data collection and a national database and biorepository developed from clinical trials and research projects.

#### ② **Mine existing data and improve data linkage between sources to improve understanding of the current state of endometriosis in Australia.**

- 2.1 Develop innovative, easy to use tools for patients and clinicians to capture valuable data.
- 2.2 Promote data translation of international research for the Australian context, to ensure that ongoing research into endometriosis benefits from the most up-to-date international information.
- 2.3 Identify existing resources and databases in Australia and pursue linkages between these data sources to enrich available data on endometriosis.

#### ③ **Conduct further research to understand the causes and impacts of endometriosis and progress towards the development of a cure.**

- 3.1 Release a targeted call for endometriosis research through the Medical Research Future Fund. Seek grant applications for Australian research that responds to identified priorities.
- 3.2 Prioritise research into the direct and indirect health system cost of endometriosis in Australia, including financial impact on the individual, the healthcare system and estimated social and economic participation loss.
- 3.3 Promote further research into the implications of endometriosis for pain and fertility, as well as the nature of disease progression and ideal approaches to symptom management and prevention.
- 3.4 Conduct further research on the epidemiology, pathogenesis and genomics of endometriosis in order to understand the causes and underlying factors that lead to the development and progression of the disease, and to pave the way for the development of a possible cure.

**3.5** Fund and commission research aiming to develop a non-invasive diagnostic test for endometriosis.

**3.6** Continue to support longitudinal research to track the burden of disease in Australia, for long-term assessment of the success of interventions and increased action on endometriosis.

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## ACHIEVING PROGRESS

The primary role of this first National Action Plan for Endometriosis is to provide high-level guidance for the planning and development of specific policies and actions related to endometriosis and chronic pelvic pain in Australia.

An effective action plan requires ongoing information about progress towards implementation as an integral part of that plan. To ensure the effectiveness of the National Action Plan in fulfilling its objectives, the following is proposed:

1. A coordinating mechanism, such as a representative Implementation Steering Group, is established to facilitate and drive implementation of the Plan; and
2. A five-year review to assess the progress made in each of the priority areas, including a representative subsection of the priorities and actions which have been recommended within this document.

### Expectations for the future

In five years' time, we would expect to see a marked improvement against the eight objectives of the National Action Plan, with indication of progress against the overarching goal of an improvement in quality of life for women and girls living with endometriosis and chronic pelvic pain. Progress against these goals may be difficult to quantify – for example, an increase in community awareness of endometriosis may result in a heightened number of diagnoses or an increase in estimated prevalence. Accordingly, direct quantitative targets – particularly at the population level – are unlikely to be useful measures.

Accordingly, the proposed review will adopt select, specific criteria through which to determine progress. These criteria will not comprehensively address each objective but are designed as a litmus test for broad-ranging progress across each of the priority areas. Table 1 lists the five proposed criteria.

**Table 1: Proposed criteria for Five Year Review of progress against the National Action Plan**

- 1 Have school menstrual education programs been implemented and embedded?
- 2 Do GPs and other healthcare professionals throughout Australia demonstrate a base-level increase in understanding of endometriosis?
- 3 Is there a publicly available resource outlining the optimal care pathways for patients with endometriosis, from first consultation through to surgical intervention?
- 4 Have Australian Clinical Care Guidelines been developed, agreed, and disseminated throughout the country?
- 5 Has the domestic research program expanded significantly, with a view to meeting international research priorities?

## NEXT STEPS

The National Action Plan priorities include a set of actions, possible in the shorter or longer term. These actions refer directly to the opportunities identified through consultation with key stakeholders and are designed to address the multilayered challenges in Australia's response to endometriosis.

It is proposed that, using the Framework for Action at Appendix A, the Implementation Steering Group coordinates effort to prioritise the actions within the Plan, identify the sector area responsible for driving implementation of each action, who the key implementation partners will be and how to progress implementation to achieve the overall objectives of the National Action Plan.

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## APPENDIX A - FRAMEWORK FOR ACTION

The following framework proposes further detail on action items, where available. The inclusion of 'sector area' is intended to emphasise a focus on collective responsibility for implementation. The 'sector area' for each action will need to be identified as part of the implementation process.

The sector area will be the part of the sector that should oversee, coordinate or initiate progress towards the action. They do not have sole responsibility for implementation but are a necessary leader in driving change among the collaborative parties.

It is proposed that this Framework for Action is used as a platform for collaborative action to drive change to achieve the objectives of the Plan.

### Priority area 1 – Awareness and education

#### ① Develop widespread, visible and context-specific community awareness campaigns delivered through multiple channels.

	Action	Detail	Sector area
1.1	Develop, promote and deliver community awareness campaigns, delivered across multiple platforms, to improve the visibility of endometriosis in public life, and to ensure that endometriosis is a widely recognised chronic condition.	<p>Improve endometriosis' visibility in public life to ensure that endometriosis ('endo') enters the public vernacular. Increased visibility should enable increased public awareness of the condition, as well as its prevalence, long-term health implications, and the appropriate routes to further information.</p> <p>Partner with industry to promote awareness across multiple platforms, including but not limited to packaging of menstrual, contraceptive and analgesic products, partnerships with health funds and sports organisations, and advertising campaigns designed for public bathrooms and other appropriate settings.</p> <p>Include a layered approach to messaging – opinion pieces and spokesperson partnerships as well as traditional advertising routes.</p>	
1.2	Support the development of endometriosis-specific media and awareness materials that are tailored for Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse groups, and for rural and regional contexts.		
1.3	Develop workplace-specific materials to educate employers on the prevalence and impact of endometriosis, to enable employers and workplace human resources departments to support employees with endometriosis in a professional setting.	Challenge schools, universities, employers and workplace human resources departments to increase education about endometriosis.	



② **Promote early education on women's health, delivered in school settings, and provided for all genders.**

	Action	Detail	Sector area
2.1	Update secondary school puberty and sexual health curriculums to include a menstrual education program resource, delivered by specially qualified personnel, to educate older students about menstrual health, the symptoms of endometriosis and related conditions. Promote access to resources for students and parents to learn more about menstrual health.	Support the expansion of the Menstrual Education (ME) Schools Program to deliver this. Support both face-to-face and online sources as tools for learning.	
2.2	Equip primary and secondary school educators, as well as physical and mental healthcare staff in these environments, to recognise the symptoms of endometriosis and provide resources, guidance and support to students.	This could involve the mobilisation of the PIPPA (Period ImPact and Pain Assessment) test in the school curriculum to monitor for early signs of menstrual disturbance, endometriosis or pelvic pain.	
2.3	Acknowledge cultural barriers and develop education programs sensitive to the expectations of different demographic groups. Deliver endometriosis education and develop resources in multiple languages, accessible to people with varying levels of literacy and from different cultural backgrounds.		



③ **Improve access to information, self-education and self-management tools for women living with endometriosis at all stages of their journey.**

	Action	Detail	Sector area
3.1	Develop and publish a clear flow diagram to map the pathway for women and girls with endometriosis or pelvic pain through the healthcare system, from first consultation through to medical intervention, to inform and enable patients to be active decision-makers and participants at each stage of care.	The map should prepare patients to be active decision-makers at each stage of disease progression. It will educate patients on the available pathway(s) and provide basic detail on what patients should ask for at each stage of their care. The journey map should span the care pathway through various healthcare services and should indicate alternatives for services that may not be available to all patients.	
3.2	Develop and promote a resource kit for women and girls newly diagnosed with endometriosis to provide general information about the condition and inform patients about where to find further resources and access support and treatment services. The kit should be provided freely and be available in both physical and discrete digital formats.	Develop a <i>My Endometriosis Journey</i> resource kit which draws on the success of the Breast Cancer Network Australia's <i>My Journey Kit</i> .	
3.3	Support the development of interactive tools (phone-based applications, web-based diagnostic tools and symptom checkers) to increase patient health literacy and promote proactive health-seeking behaviour.		
3.4	Promote existing and emerging information sources that acknowledge cultural differences around discussion of women's health and menstruation and ensure these can be accessed discreetly online through multiple sources.	Promote the availability of these online resources through multiple, public sources including social media, school and university settings, community centres, etc.	

④ **Improve awareness and understanding of endometriosis among health professionals working at every stage in the clinical pathway.**

	Action	Detail	Sector area
4.1	Provide general practitioners (GPs) with concise educational materials on the prevalence, symptoms and treatment options for endometriosis, both for their own professional development and for distribution to patients. Ensure that GPs are encouraged to refer patients with pelvic pain symptoms through the appropriate care pathways.	Implement 'train the trainer' educational programs for GPs who work in educational or regional and rural contexts, and for voluntary members of all other general practices to attend and distribute information back to their practices. Emphasise the role of gynaecologists in the development of health plans. Supplement interactive digital tools with desktop resources for use in individual consultations, which can be provided to GPs for distribution to women and girls who have pelvic pain symptoms.	
4.2	Educate ultrasound technicians, ultrasound specialists, radiologists and physiotherapists on the symptoms of endometriosis and enable them to assess and identify endometriosis symptoms as part of routine services for pelvic pain or	Update guidelines for routine ultrasounds for women to include assessment for endometriosis, including reporting of symptoms in follow-up with GP. Raise the level of gynaecological ultrasound assessment to look at deep endometriosis as part	

	Action	Detail	Sector area
	related conditions.	of the assessment.	
4.3	Educate clinicians, allied health professionals and others involved in endometriosis care on the prevalence, symptoms and available pathways for treatment and embed pain management guidance into educational programs.	Include pharmacists, nurse practitioners, surgeons, emergency department (ED) triage staff, and ED physicians in the process. Pain management guidance needs to assist with shorter term management as well as longer term referral.	
4.4	Update teaching and training standards to include endometriosis-specific education and include learning modules on endometriosis in training for all relevant specialties, across tertiary and vocational medical training programs.	Promote partnerships between relevant specialist colleges and medical schools to deliver specialised training on endometriosis and pelvic pain. Engage medical student associations to support the rollout of education programs and awareness campaigns. Inclusion of pain training across relevant medical and allied health specialties.	
4.5	Facilitate advanced training for interested health professionals to provide an advanced level of expertise in endometriosis and pelvic pain diagnosis, treatment and management.	Upskill a sub-group of GPs to be endometriosis and pelvic pain specialists.	

## Priority area 2 – Clinical management and care

### 1 Ensure endometriosis is recognised as a chronic condition by all health practitioners, acknowledging its physical, psychological and social impacts.

	Action	Detail	Sector area
1.1	Inform and educate health professionals about the psychological and social impacts that chronic pain and under-recognition of endometriosis has on women and girls living with the condition, and ensure access to appropriate resources, social and psychological support mechanisms, and holistic care.	PHNs to strengthen pathways between GP, specialist and mental health services, to promote horizontal and vertical integration between the numerous primary care services used by patients with endometriosis.	
1.2	Inform and educate health professionals about the potential long-term impacts on fertility and provide support to health professionals to encourage patients with endometriosis to consider fertility and future options.	Provide resources and access to information and support through online forums, advocacy and women's health website and social media presences, and fertility-specific information sources and healthcare providers.	

② **Develop clinical guidelines and clinical care standards to promote integrative care for all stages of the care pathway.**

	Action	Detail	Sector area
2.1	Revise, adapt and incorporate existing, international clinical guidelines on endometriosis to develop authoritative clinical guidelines and clinical care standards for health services and health practitioners throughout Australia.	Consider adapting the UK's National Institute for Health and Care Excellence guidelines on endometriosis. These documents should uphold both the safety and quality of care and promote collaboration between multidisciplinary centres of excellence and centralised networks of expertise in the development process.	
2.2	Define and document ideal evidence-based patient pathways from self-information, GP consultation through to senior specialist care, providing as a national clinical resource to guide referral and progressive movement of patients through the care system.	Embed a standardised procedure involving listening to the patient's story, experience, and family history, followed by pelvic pain examination and ultrasound. Acknowledge the need for minor adjustment or individualisation of the care pathway through instituting a patient-centred approach.	
2.3	Establish clear models of care (MOC) for self-management, medical management and/or surgical management of endometriosis. Develop clear clinical and plain English resources to outline best practice MOC and distribute to healthcare professionals as well as patients.	MOC must be adaptable for various contexts and settings in the Australian healthcare landscape, including regional and rural service providers, must be implementation-focused, and should aid quality assurance and the nationalisation of standards across all services. MOC should cover endometriosis lesions, pain management, fertility management and management of psychosocial aspects of living with endometriosis.	
2.4	Consider routes to develop surgical accreditation standards and assessment processes for laparoscopic surgeons, to lift the quality of laparoscopic surgery throughout the country and minimise the need for repeated invasive surgery for endometriosis.		

③ **Target diagnostic delay and promote early access to intervention, care, and treatment options for women and girls.**

	Action	Detail	Sector area
3.1	Devise and promote a simple, standardised and easily accessible tool to aid or precede diagnosis, that can be completed by women with potential symptoms of endometriosis prior to a GP appointment, to encourage early action and intervention.	A questionnaire or screening assessment. Publish online and distribute through patient networks, schools and via healthcare providers. Develop a more robust and accessible version of the PIPPA (Period ImPact and Pain Assessment) test or the PPFA questionnaire to accompany or contribute to this screening process.	
3.2	Clearly identify criteria to determine when follow-up interventions are needed for formal diagnosis or treatment, in order to improve triage processes for multidisciplinary endometriosis care.	Include in the patient care pathway. For where a GP consultation, transvaginal ultrasound, laparoscopy or other intervention is needed. Delineate the roles of different forms of informal diagnosis and best practice 'next steps' for various	

	Action	Detail	Sector area
		markers of disease, including indicators of psychosocial impact.	
3.3	Create and support informal educational, advocacy and support networks, providing information on available clinical services and helping patients navigate the system.	Networks to highlight existing clinical and education tools to clarify the care pathway for an individual at any stage of disease progression, from new symptoms to established care.	

**4 Improve the affordability, accessibility and national consistency of management and care options for women throughout Australia.**

	Action	Detail	Sector area
4.1	Develop and deliver a national rollout of clinical guidelines and clinical care standards, to ensure that services are provided at a uniform baseline quality across the country.	The development of the guidelines should be complemented by the development of a reporting mechanism, assessment or initiative to ensure that clinical guidelines are being observed and maintained at a national level.	
4.2	Support the dissemination of best practice information and approaches throughout services in Australia.	Including guides to the nurse-led care and support mechanisms developed at the Canberra Endometriosis Centre and examples of best practice in ultrasound and radiology	
4.3	Develop a phone-based application for clinicians to support the observation of symptoms of endometriosis and clarify 'next steps' for referral at any stage of the care pathway.		
4.4	Ensure no populations or demographics 'fall through the gaps' by integrating clinical guidance on endometriosis into guidelines for services targeted towards vulnerable and at-risk groups.	Specifically, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse populations, women and girls in rural and remote settings, adolescents and transgender men.	
4.5	Develop messaging to patients with endometriosis to reassure them that any conversations with their GP or healthcare provider regarding their sexual or reproductive health is confidential.	Ensure that information and resources on endometriosis, pelvic pain and menstrual and reproductive health can be accessed discretely, through web or phone-based information sources, to reduce the impact of stigma as a barrier to education.	
4.6	Reduce barriers to assessment and treatment by pursuing options to reduce the cost of consultations and medications for women and girls with endometriosis and pelvic pain.	Through the Medical Benefits Schedule (MBS) Review, seek a review of relevant consultation and treatment items. Consider partnering with pharmaceutical companies to pursue Pharmaceutical Benefits Scheme listing for endometriosis medications, including hormone replacement therapy (HRT) medications.	

5

## Narrow the gap in quality of life between patients and their peers.

	Action	Detail	Sector area
5.1	Improve access to, and encourage patients to consult with, hormone-based pain management specialists to reduce day-to-day impact on personal life, contribution and social and economic participation, leading to improved outcomes.	Ensure patients with endometriosis have adequate access to appropriate medications and complementary and alternative medicine regardless of their ability to pay for specialist treatment or consultation.	
5.2	Use clinical care standards to optimise outcomes for women and girls with endometriosis, ensuring the right care at the right time in the right place.	Seek to minimise surgical interventions where possible and encourage patients to seek a second opinion when referred for laparoscopy. Include reference to the emotional effects of repeated surgeries in professional educational materials and disseminate information on alternatives to surgical intervention when deemed clinically appropriate.	
5.3	Promote strong multidisciplinary teams by strengthening clinical pathways between specialists involved in the daily management of endometriosis symptoms.	Including pain specialists, pelvic floor specialists, psychologists, counsellors and other specialists.	

## Priority area 3 – Research

### 1 Build a collaborative environment that enables world-leading research on endometriosis.

	Action	Detail	Sector area
1.1	Establish a national Clinical Trials Network that coordinates support for research organisations to conduct clinical trials for endometriosis treatments and services.	Use the network to compile resources from hospitals, universities and research institutions and to oversee the discerning use of clinical trials to substantiate research and draw out actionable clinical outcomes. Improve evidence base through recruiting and coordinating larger, randomised cohorts where possible.	
1.2	Develop an Australian Research Collaboration Framework to support coordinated patient recruitment, consistent data collection and a national database and biorepository developed from clinical trials and research projects.		

### 2 Mine existing data and improve data linkage between sources to improve understanding of the current state of endometriosis in Australia.

	Action	Detail	Sector area
2.1	Develop innovative, easy to use tools for patients and clinicians to capture valuable data.	Apps, image capture and processing, computer-based questionnaires, record linkages, central databases, etc.	
2.2	Promote data translation of international research for the Australian context, to ensure that ongoing research into endometriosis benefits from the most up-to-date international information.		
2.3	Identify existing resources and databases in Australia and pursue linkages between these data sources to enrich available data on endometriosis.	Support further data mining and linkage between existing resources and databases in Australia. Use available and emerging longitudinal data from the Longitudinal Study on Women's Health to determine the average age of onset of endometriosis (from available regions) as well as long-term health implications for women with endometriosis, including changes in health outcomes following surgery or menopause.	

3 **Conduct further research to understand the causes and impacts of endometriosis and progress towards the development of a cure.**

	Action	Detail	Sector area
3.1	Release a targeted call for endometriosis research through the Medical Research Future Fund. Seek grant applications for Australian research that responds to identified priorities.		
3.2	Prioritise research into the direct and indirect health system cost of endometriosis in Australia, including financial impact on the individual, the healthcare system and estimated social and economic participation loss.	Seek to understand the direct and indirect health system cost of endometriosis in Australia. Capitalise on existing Australian datasets to understand the historic burden and change over time, as well as existing international datasets for comparison and baseline assessment.	
3.3	Promote further research into the implications of endometriosis for pain and fertility, as well as the nature of disease progression and ideal approaches to symptom management and prevention.	Support research and trials into the effectiveness various complementary and alternative medicines, physiotherapy, psychological interventions or behavioural interventions for relieving the symptoms of endometriosis, in order to establish what therapies work and under what circumstances. Coordinate research with the establishment of the National Clinical Trials network.	
3.4	Conduct further research on the epidemiology, pathogenesis and genomics of endometriosis in order to understand the causes and underlying factors that lead to the development and progression of the disease, and to pave the way for the development of a possible cure.		
3.5	Fund and commission research to develop a non-invasive diagnostic test for endometriosis.	Collaborate with gynaecological specialists, sonologists and radiologists to determine effective alternatives to laparoscopy to determine the presence of endometriosis symptoms. Scope the potential of ultrasound to detect superficial lesions as well as deep infiltrating endometriosis.	
3.6	Continue to support longitudinal research to track the burden of disease in Australia, for long-term assessment of the success of interventions and increased action on endometriosis.		



## APPENDIX B - IMPLEMENTATION PARTNERS

Implementation partners include organisations from across various sectors, operating at local, state, territory and national levels. Dependent on the priority and action, partners may be required to work in direct collaboration or in parallel. Proposed partners include education providers and peak bodies; primary, secondary and tertiary healthcare providers; general practice, allied health and specialist colleges and representative bodies; researchers; advocates; industry groups; industry partners; the media; and policymakers and governments.

Below is a summary of key partners, who are required to collaborate across all three focus areas to enable the delivery of numerous actions. Following this are specific partners required for each of the three focus areas to enable successful implementation of the actions.

### Key Partners

- Commonwealth and State and Territory Governments
- Advocacy groups and women's health organisations
- Clinicians
- Patients, caregivers and patient peak body associations
- Royal Australian College of General Practitioners (RACGP)
- Canberra Endometriosis Centre
- Primary Health Networks (PHNs)
- Australian Medical Council (AMC)
- Tertiary medical schools and vocational medical training institutions
- The Australian College of Applied Psychology (ACAP)
- Australasian College of Emergency Medicine (ACEM)
- Australasian Gynaecological Endoscopy & Surgery Society (AGES)
- Australian Physiotherapy Association (APA)
- Australasian Society for Ultrasound in Medicine (ASUM)
- Australian College of Rural and Remote Medicine (ACCRM)
- Australian Medical Association (AMA)
- Australian Medical Students' Association (AMSA)
- Australian Practice Nurses Association (APNA)
- Pharmacy Guild of Australia
- Royal Australasian College of Surgeons (RACS)
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- Royal Australian and New Zealand College of Psychiatrists (RANZCP)
- Royal Australian College of Physicians (RACP)
- Royal Australasian College of Radiologists (RANZCR)
- Urological Society of Australia and New Zealand
- The Fertility Society of Australia (FSA)
- Researchers and research institutions



## Specific to priority area 1

### Partners

- All Departments of Education
- Educational institutions, particularly health providers located in these environments
- Primary and secondary schools, including public, private, independent and faith-based systems
- Teaching peak bodies – private, religious and public
- Mothers, fathers and parental figures
- School nurses and health educators
- Media
- Employers and workplace human resources (HR) departments
- Industry partners, spanning multiple consumer products and services
- Sporting organisations, particularly women's sports leagues
- Australian Institute of Company Directors (AICD)
- Australian Retailers Association (ARA)

## Specific to priority area 2

### Partners

- Australian Commission on Safety and Quality in Healthcare
- Aboriginal Community Controlled Health Organisations (ACCHOs)
- Pharmaceutical industry, particularly manufacturers of analgesics, hormonal therapies and endometriosis-specific medications

## Specific to priority area 3

### Partners

- Medical Research Future Fund
- National Health and Medical Research Council
- Association of Australian Medical Research Institutes
- Australian Society for Medical Research
- Researchers and research institutions, including the Longitudinal Study on Women's Health, in collaboration with international research bodies

## APPENDIX C - REFERENCES

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