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FINAL REPORT
of the
SELECT COMMITTEE ON ENDOMETRIOSIS

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INTRODUCTION BY THE CHAIR

Endometriosis is a condition that affects millions of individuals worldwide, yet its personal impact often goes unnoticed or misunderstood. One in seven women are diagnosed with endometriosis in Australia, but given the time it takes to get that diagnosis, the number of sufferers is likely much higher.

As someone who has battled endometriosis, I know firsthand how it can disrupt daily life, relationships, career, and even one's identity. The pain can be debilitating, but it is the less tangible effects—such as the uncertainty, the misdiagnoses, and the struggle to be understood—that often makes this condition particularly isolating. The journey is filled with moments of frustration and perseverance, as one seeks answers, treatments, and understanding

For me, this report is more than just a Select Committee enquiry – it's a reflection of my own journey with endometriosis. The symptoms, often invisible to the outside world, bring daily challenges that range from physical pain to emotional and psychological stress.

One of our witnesses really encapsulated how many sufferers' mental health is impacted with a simple sentence and a cry for help - every month 'the pain is waiting for me.'

The committee received 85 submissions, and we would like to thank every sufferer who had the courage to document their journey, to those who came and presented to us in person and to all of their families who support them.

Through this report and its recommendations, the committee hopes that those who provided personal stories know they have now been heard.

We would also like to thank the many academics, government agencies, health and medical professionals, not-for-profit organisations and sector unions for giving evidence and for all of the work that they do to support people living with this disease.

It is my sincere hope that this inquiry will foster greater awareness, empathy, and support for those affected by endometriosis, and contribute to the growing conversation around better diagnosis, treatment, and care. Sufferers are not just numbers or statistics – they are individuals navigating a challenging path, and their voices and experiences deserve to be heard.

Based on the evidence heard and received, the committee has made 20 recommendations with the aim to reduce the time taken for diagnosis and for individuals who battle every day to have better health outcomes.

I would like to thank all of our committee members for their input and deliberation of the evidence we received. It was quite an emotional journey but also very informative. A special thanks goes to our Parliamentary Officer, Research Officer and Hansard staff for their support and assistance.

It is through greater understanding and awareness that together, we can make strides towards improving the lives of those impacted by this often misunderstood condition.

Catherine Hutchesson

Ms Catherine Hutchesson MP
Chair
19 March 2025

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2. EXECUTIVE SUMMARY

The Parliamentary Select Committee on Endometriosis was established pursuant to a resolution in the House of Assembly on Thursday 21 March 2024, on the motion of Ms Catherine Hutchesson MP, to inquire into and report on the following: a) the number of women in South Australia who suffer from endometriosis; b) the current treatment and supports available; c) the barriers to getting a diagnosis, gaining access to treatment and management options and pathway; d) the impacts to employment of sufferers and employer's best practice in supporting those with endometriosis; e) education available to young women, professionals and others; f) research and trials currently being explored in Australia; and g) any other related matters.

Endometriosis is a chronic inflammatory condition where cells like those lining the uterus grow outside the uterus. Endometriosis is considered a common but underdiagnosed inflammatory condition that affects girls, women and those assigned female at birth (AFAB). The disease has no cure, but several treatment and management options are available.

The committee invited submissions from all interested parties over three months beginning in April 2025. The committee received evidence from various stakeholders, with 85 submissions from individuals with endometriosis or their family members, academics, government agencies, health and medical professionals, medical facilities, networks and medical associations, not-for-profit organisations, and sector unions. The committee met on 16 occasions to receive oral evidence, including two regional hearings, one in Berri on Tuesday 12 June 2024 and another in Mount Gambier on Wednesday 18 September 2024. Seventy-four witnesses presented oral evidence from 10 April to 27 November 2024.

Evidence for the inquiry was sought via various mainstream and social platforms, including the Parliament of South Australia's Facebook and X accounts. Formal letters were also sent to Members of both South Australian Houses of Parliament to promote the committee and encourage the Members to advertise the inquiry in their respective electorates. Additional promotional activities were undertaken for the regional hearings, which included advertisements placed in local newspapers, radio interviews by the committee Chair, and direct contact with key local stakeholders, such as local health networks and schools, local Member of Parliament, and social media.

The prevalence of endometriosis in South Australia is deemed similar to the national estimate from the Australian Longitudinal Study on Women's Health, which is 1 in 7 women born in 1973–78 have been diagnosed with endometriosis by age 44–49 and by age 31, many of those in the younger cohort would have been diagnosed to have the disease as well. These figures tell that endometriosis hits girls, women, and those AFAB at the prime of their lives, affecting their bodies, personal and social relationships and functions. The evidence presented to the committee indicates that the impact of endometriosis goes beyond the individual as it also strains the health system and overburdens a limited workforce due to frequent hospitalisations and emergency department presentations and the long waitlist to see relevant health and medical practitioners. These scenarios contribute to the long delays – about six years in getting a diagnosis, treatment, and management.

In the past, laparoscopy was the only method to diagnose endometriosis, contributing to more delays in confirming the condition. Transvaginal ultrasound scans and magnetic resonance imaging have recently been endorsed as diagnostic tools. Options for the treatment and management of endometriosis consist of a variety of techniques, including the use of analgesics, hormone therapies, non-drug and non-hormonal treatment, surgery, and even opioids and pelvic floor Botox.

Given this smorgasbord of treatment and management alternatives, approaches to holistically address the multi-faceted impact of endometriosis is needed. The current and proposed structures to facilitate early diagnosis, treatment, and management of endometriosis noted in the evidence provided to the committee was the general practitioner-led multidisciplinary care approach, increase in endometriosis clinics or dedicated pain clinics in public hospitals, with the inclusion of a nurse specialist or coordinator, and non-medical platforms.

The challenges towards seeking diagnosis, treatment, and management for endometriosis are mainly due to the following factors: 1) the normalisation of pain; 2) timely access to and availability of health and medical professionals and services; 3) cost; 4) knowledge, expertise and attitude of health and medical providers; and 5) education and health literacy among adolescents and families or carers. These elements contribute to delays in diagnosis, treatment, and management of the disease that, in many cases, result in people with endometriosis being in a worst health state.

Endometriosis impacts on people’s work - either preventing them from attending work or if at work, not able to function to their full capacity. These conditions are referred to as absenteeism and presenteeism, respectively. The decrease in an individual’s productivity due to endometriosis may cause the person to reduce their hours of paid work or lose the job. This situation further strains the person’s financial resources, including paying for endometriosis treatment and management, which can affect the person’s wellbeing and life trajectory. Hence, workplace policies and arrangements, such as reproductive health leaves and flexible work arrangements, could address issues of absenteeism and presenteeism. Additionally, having leaders, managers, and colleagues who are well-informed about endometriosis and supportive of employees suffering from the condition can make a big difference in the workplace.

The evidence provided to the committee also outlined that continuing education about endometriosis among health and medical professionals, and early knowledge and awareness of the condition among young people and their personal and social relations, is crucial towards employing a holistic approach in diagnosing, treating, and managing the disease.

With the current progress in diagnosis, treatment and management options, health economics research and impact studies are required to gauge the implications of these developments for bettering the lives of people living with endometriosis.

The select committee has generated recommendations, particular to the terms of reference of this inquiry. These recommendations delve into supporting health and medical practitioners, researchers, advocacy and support groups, the general public, and most importantly, people with endometriosis towards achieving an ideal timeframe in diagnosing, treating, and managing endometriosis. The committee also hopes the recommendations will facilitate an increased exchange of updated information and outcomes of clinical trials and other research initiatives to bolster the delivery of primary services in South Australia relevant to endometriosis treatment and management. Ultimately, the committee's recommendations aim to address the delay in diagnosis and the challenges to building and accessing the holistic care approach for treating and managing endometriosis.

3. SUMMARY OF RECOMMENDATIONS

The key outcome the committee wants this inquiry to achieve is a reduction in the time taken to diagnose endometriosis – from an average of 6 years to 1 year, and for individuals with the conditions to have better health outcomes.

To achieve this, the committee recommends that:

1. All tertiary training for GPs, gynaecologists, sonographers and allied health professionals to place a greater emphasis on the identification and management of endometriosis.

2. SA Health support doctors, nurses, sonographers and allied health practitioners to undertake professional development in endometriosis and pelvic and period pain diagnosis, treatment and management in order to increase the number of clinicians in the public health sector including emergency departments able to diagnose, treat and manage individuals with endometriosis.

3. The State and Commonwealth governments assess existing chronic pain clinics' ability to provide specialist care to endometriosis patients and work together to establish more specialist endometriosis or chronic pain clinics, including public health endometriosis and chronic pain clinics.

4. SA Health consider what a best practice model of multidisciplinary care to diagnose, treat and manage endometriosis could be and work with regional service providers, including private practitioners, to utilise face-to-face as well as telehealth to best suit their community.

5. The Commonwealth and State Governments support and incentivise doctors, nurses, sonographers and allied health practitioners with endometriosis training to work in regional, remote, and rural areas, as well as increased access to imaging facilities.

6. SA Health work with RACGP to develop, produce and disseminate endometriosis-information kits to GP clinics to give to individuals with endometriosis and others with pelvic pain disease across South Australia.

7. Local Health Networks (LHNs) review how presentations to their emergency departments due to pelvic pain and endometriosis are clinically assessed and managed, including the specific number of presentations so that accurate data can be collected.

8. State Government work with local health networks and other health advisory organisations to increase the knowledge in the community regarding endometriosis and the availability of specialist services and practitioners in their local area. Through this process, identify gaps in their local areas of allied health/ other medical professionals and work with SA Health to access telehealth to fill these gaps.

9. The State Government consider the benefit of establishing a virtual health service for women to reduce barriers and delays in accessing care and support for endometriosis and other women’s health issues.

10. The Commonwealth Government, in conjunction with relevant associations, undertake an education campaign to GPs and gynaecologists regarding

    - available Medicare rebates that allow GPs to refer patients for TVUSS to diagnose endometriosis;
    - Medicare rebates for gynaecologists to participate in multidisciplinary care teams; and
    - the updated international and national guidelines that recognise contemporary diagnostic techniques, such as imaging, and contemporary treatment options, such as physiotherapy and nutrition, for individuals with endometriosis.

11. The Commonwealth Government work with the RACGP and researchers to assess any existing and/or develop an endometriosis symptom checklist and make it available to all GPs to assist them with their patients.

12. The State Government prepare a broad-base public health campaign regarding endometriosis and other inflammatory pelvic pain symptoms to increase information dissemination to the wider community, and encourage the Local Government Association to work with its councils to do the same.

13. The State Government to work with the Commonwealth Government, as a matter of urgency, for Medicare to include a specific item number for endometriosis diagnostic imaging.

14. The State and Commonwealth Governments work together to investigate alternative treatments for endometriosis, such as Botox, and consider its inclusion in the MBS if shown to be an appropriate alternative.

15. The Commonwealth Government inquire into the barriers that lead to delays in PBS listings of medicines that can be utilised to manage endometriosis, and ensure that efficient government processing is in place.

16. The State Government

    - continue to fund education sessions for students regarding reproductive health, pelvic pain and endometriosis;
    - ensures these sessions are provided in all public schools where possible, and encourage private schools to do the same;
    - look to expand this funding to include sporting clubs and sessions for parents; and
    - fund educational campaigns and promotional materials using both mainstream and social media platforms, the back of toilet doors where appropriate, targeted at all public educational institutions (especially secondary and tertiary).

17. The State Government lobby for the Australian Curriculum to be updated when it is next reviewed, to include improved education content on menstruation, pelvic pain and what is normal and abnormal.

18. The State Government facilitate a stakeholder forum inviting members of leadership and management teams, from both private and public sectors and unions, to discuss and exchange experiences and ideas in dealing with employees who have reproductive health challenges, including endometriosis.

19. The State Government assess current flexible work arrangements available to public sector employees to ensure they are providing staff with the flexibility they need when they are managing their serious pelvic pain, and consider the introduction of reproductive health leave, in addition to sick leave, for people with chronic reproductive health issues.

20. The Commonwealth Government increase and prioritise funding and support for women's reproductive health research as well as clinical trials involving girls, women, and those AFAB, especially on health matters that are commonly or exclusively experienced by these cohorts, including endometriosis.

ABBREVIATIONS

AFAB	Assigned female at birth
ACTU	Australian Council of Trade Unions
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
Botox	Botulinum toxin or botulinum neurotoxin
CDMP	Chronic disease management plan
DHAC	Department of Health and Aged Care
ESHRE	European Society of Human Reproduction and Embryology
GP	General practitioner
GnRHa	Gonadotrophin-releasing hormone analogues
IUD	Intrauterine device
JAECE	Julia Argyrou Endometriosis Center Epworth
MRI	Magnetic resonance imaging
MBS	Medicare Benefit Schedule
NAPE	National Action Plan for Endometriosis
NECST	National Endometriosis Clinical and Scientific Trials Network
NES	National Employment Standards
PPFA	Pelvic Pain Foundation of Australia
PPEP Talk®	Periods, Pain and Endometriosis Program
PPP	Persistent Pelvic Pain
PPPC	Persistent Pelvic Pain Clinic
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
QENDO	Queensland Endo
QCU	Queensland Council of Unions
RATE	Raising Awareness Tool for Endometriosis
RACGP	Royal Australian College of General Practitioners
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologist
TVUSS	Transvaginal ultrasound scan
YPPPC	Yorke Peninsula Pelvic Pain Clinic

All dollar amounts are in Australian dollars.

4. ESTABLISHMENT OF THE COMMITTEE

4.1 Appointment of the Committee

On Thursday 21 March 2024, on the motion of Ms Catherine Hutchesson MP, Member for Waite, the House of Assembly agreed to establish a select committee to inquire into and report on the impact of endometriosis on individuals' lives and the South Australian community, barriers to getting a diagnosis and accessing treatment and ongoing pain management, treatment options and supports available, accessible education about the disease, and current research and trials.

4.2 Membership

The membership of the select committee appointed by the House of Assembly consisted of the following members:

Ms Catherine Hutchesson MP (Chair)	Member for Waite
Hon Leon Bignell MP	Member for Mawson (until 14 May 2024)
Mr Lee Odenwalder MP	Member for Elizabeth (from 14 May 2024 to 18 June 2024)
Ms Cressida O'Hanlon MP	Member for Dunstan (from 18 June 2024)
Hon David Pisoni MP	Member for Unley
Ms Penny Pratt MP	Member for Frome
Ms Dana Wortley MP	Member for Torrens

Ms Hutchesson was elected Chair of the select committee. Ms Alison Meeks was assigned the role of Secretary and Dr Jennefer Bagaporo the role of Research Officer to the committee for the whole of the inquiry.

4.3 Terms of Reference

The Select Committee's Terms of Reference, as agreed by the House of Assembly, were to inquire into and report on:

(a) the number of women in South Australia who suffer from endometriosis;
(b) the barriers to getting a diagnosis, gaining access to treatment including primary care, specialist clinics and ongoing pain management;
(c) the current treatment and supports available, their evidence-based effectiveness and potential side effects and impacts;
(d) the impacts to employment of sufferers and employer best practice in supporting women with the condition;
(e) education available to young women, professionals and others;
(f) research and trials currently being explored in Australia; and
(g) any other related matters.

4.4 Disclosure of Evidence

Pursuant to Standing Order 339, the select committee has power to authorise the disclosure and publication, as it sees fit, of any evidence presented to the committee prior to such evidence being reported to the House.

4.5 Conduct of Inquiry

The committee invited submissions from all interested parties over a 3-month period, from April 2025. Submissions were still accepted after June 2025. Advertisements were placed in the Advertiser (on Saturday 6 April), local regional papers during April, the Stock Journal and in InDaily. The Parliament of South Australia's Facebook and X accounts were also utilised to advertise the committee's call for submissions. Additionally, a formal letter was sent to Members of both Houses to promote the committee and encourage the Members to advertise the committee in their respective electorates.

The committee received evidence from a variety of different stakeholders. During the course of the inquiry, the committee received 85 submissions from individuals who have endometriosis or their family members, academics, government agencies, health and medical professionals, medical facilities, networks and medical associations, not-for-profit organisations, and sector unions (Appendix 17.1).

The committee met on 16 occasions to hear from witnesses, including in two regional locations (Appendix 17.2). The two regional hearings were held in Berri, on Tuesday 12 June 2024, and in Mount Gambier, on Wednesday 18 September 2024. In addition to the above advertisements, additional promotional activities were undertaken for the regional hearings, which included advertisements placed in local papers, radio interviews by the committee Chair, phone calls to key local stakeholders including local health networks and schools, the local Member of Parliament and social media.

A total of 74 individuals presented oral evidence from 10 April to 27 November 2024. All witness hearings were transcribed by Hansard. The transcripts were sent to witnesses and committee members for review. Witnesses were instructed that any corrections they make should be confined to a) statements wrongly attributed and/or b) word (s) and/or figure(s) wrongly transcribed by Hansard. Corrected Hansard transcripts of the hearing are available on the committee website.

5. BACKGROUND TO THE INQUIRY

5.1 Endometriosis

On Thursday 21 March 2024, on the motion of Ms Catherine Hutchesson MP, Member for Waite, the House of Assembly passed a resolution to establish a select committee on endometriosis. As someone with endometriosis, Ms Hutchesson reflected on her experience with the disease, noting endometriosis' debilitating effect on both personal and social aspects of the lives of people who suffer from the condition.

Endometriosis is a chronic inflammatory condition affecting girls, women and those assigned female at birth (AFAB), where cells similar to those that line the uterus grow outside the uterus.[1] These endometrial cells 'form lesions or patches that bleed and leak fluid in response to hormones at the time of the period, leading to inflammation and scarring.'[2] Endometrial-like tissues are usually found around the pelvis,[3] but cases of these tissues occurring outside the pelvic cavity, such as the bladder and bowel, have been noted.[4]

Endometriosis is considered a common, but underdiagnosed condition.[5] The true cause of endometriosis remains unclear,[6] though related literature articulates that the condition might be due to multiple factors[7] such as those that are period-related,[8] 'a variety of environmental and immune factors',[9] and family history.[10] Recent studies have reported that genetics or having a family history of endometriosis as strongly correlated to having the disease.[11] The

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[1] Commonwealth of Australia, *National Action Plan for Endometriosis,* Department of Health, 2018; Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Australian clinical practice guideline for the diagnosis and management of endometriosis,* RANZCOG, 2021, accessed 17 July 2024; SHINE SA, *Endometriosis* [fact sheet], SHINE SA, 2019; Also see Committee Hansards: Jane Chalmers, 10 April 2024; Robinson Research Institute (Professor Louise Hull), 15 May 2024; Submissions: 20, 42.

[2] SHINE SA, *Endometriosis Fact Sheet.*

[3] See for example Committee Hansard: Jane Chalmers, 10 April 2024; Submissions: 42.

[4] Australian Institute of Health and Welfare (AIHW), *Endometriosis,* AIHW website, 2024, accessed 22 March 2024; Also see Committee Hansards: Robinson Research Institute (Professor Louise Hull), 5 May 2024; RANZCOG (Dr Magdalena Halt), 10 July 2024; Submissions: 47, 59 .

[5] J Crump, A Suker and L White, "Endometriosis: A review of recent evidence and guidelines', *Australian journal of general practice*, 2024, 53(1/2): 11-18, doi: 10.31128/AJGP/04-23-6805, p.17.

[6] J Crump, A Suker and L White, "Endometriosis: A review of recent evidence and guidelines'; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*.

[7] SHINE SA, *Endometriosis Fact Sheet.*; CHM Ng, AG Michelmore, GD Mishra, GW Montgomery, PA Rogers and JA Abbott, 'Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper', *Reproduction & Fertility,* (2023). 4(2):e230014, doi: 10.1530/RAF-23-0014; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*.

[8] CHM Ng, et al., Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper; SHINE SA, *Endometriosis Fact Sheet*; World Health Organization (WHO), *Endometriosis,* WHO website, 2023, accessed 27 March 2023.

[9] SHINE SA, *Endometriosis Fact Sheet*, no page numbers; CHM Ng, et al., Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper; AIHW, *Endometriosis.*

[10] SHINE SA, *Endometriosis Fact Sheet*, no page numbers; CHM Ng, et al., Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper; Commonwealth of Australia, *National Action Plan for Endometriosis*.

[11] AIHW, 2019. *Endometriosis in Australia: prevalence and hospitalisations*, https://www.aihw.gov.au/getmedia/a4ba101d-cd6d-4567-a44f-f825047187b8/aihw-phe-247.pdf?v=20230605184237&inline=true, accessed 08 December 2024; Jean Hailes for Women's Health, Endometriosis: Symptoms & causes, Jean Hailes for Women's Health website, 2023, accessed 6 December 2024; CHM Ng, et al., Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper.

evidence received by the committee from individuals who have endometriosis exemplifies this finding.[12]

> I recollect mum upset, worried and unsure how to help, knowing deep down something isn't right and what I'm going through isn't okay. Having been through it herself at my age, into her twenties and thirties, she could see history was repeating itself and she only hoped I wouldn't suffer as she did.[13]
>
> Going through high school, university and even into the work field I would have never even heard the word if it wasn't for my sister and mum who suffer from [e]ndometriosis. When I went to my first gynaecologist over 10 years ago, I was dismissed, and they didn't even mention the term except when I said I have a family history of it.[14]

The common symptoms of endometriosis include period and pelvic pains,[15] fatigue,[16] pain during urination or passing bowel motions,[17] pain during sexual intercourse,[18] and infertility.[19] The evidence provided to the committee, especially those from individuals with endometriosis, also notes these symptoms, with many reiterating experiencing mostly severe period and/or pelvic pain[20] and a number having a combination of these symptoms.[21]

> … I am 38 and I have always had heavy and painful periods since my menstrual cycle started when I was 14. I always get erratic cycles and lengthy cycles, heavy flooding periods often with heavy clotting, headaches, nausea, bladder leakage, lower intense back pain, pain during sex, constant and painful cramping across my lower abdomen, cysts and problems with my bowel including bleeding and pain.[22]

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[12] See for example Committee Hansard: Berri hearing (Kaye Schober), 12 June 2024; Submissions: 2, 6, 26, 60, 80, 81.

[13] Submission: 60, p. 2.

[14] Submission: 80, p. 5.

[15] M Armour, D Ciccia, C Stoikos, and J Wardle, 'Endometriosis and the workplace: Lessons from Australia's response to COVID-19', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 2022, 62(1): 164-167, doi: 10.1111/ajo.13458; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*.

[16] M Armour, et al., 'Endometriosis and the workplace: Lessons from Australia's response to COVID-19'; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*.

[17] N Giese, E Gilbert, A Hawkey and M Armour, 'Unmet Needs of Australians in Endometriosis Research: A Qualitative Study of Research Priorities, Drivers, and Barriers to Participation in People with Endometriosis', *Medicina*, 2023, 59 (9): 1655, doi:10.3390/ medicina59091655; M Leonardi and G Condous, 'Noninvasive U/S Dx of endometriosis: Can technology help provide answers to a complex condition? This guide demonstrates how to use ultrasound as a first-line diagnostic tool', *Contemporary OB/GYN*, 2020, 65(3).

[18] JC Avery, A Deslandes, SM Freger, M Leonardi, G Lo, G Carneiro, G. Condous, ML Hull, 'Noninvasive diagnostic imaging for endometriosis part 1: a systematic review of recent developments in ultrasound, combination imaging, and artificial intelligence', *Fertility and Sterility* 2024, 121(2): 164-188, 10.1016/j.fertnstert.2023.12.008; M Leonardi and G Condous, 'Noninvasive U/S Dx of endometriosis: Can technology help provide answers to a complex condition? This guide demonstrates how to use ultrasound as a first-line diagnostic tool'.

[19] M Leonardi and G Condous, 'Noninvasive U/S Dx of endometriosis: Can technology help provide answers to a complex condition? This guide demonstrates how to use ultrasound as a first-line diagnostic tool'; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*.

[20] See for example Committee Hansards: Berri Hearing (Amara Turner), 12 June 2024; Deanna Flynn-Wallis, 19 June 2024; Amy Aikman, 10 July 2024; Lucy Savage, 18 June 2024; Gayelene Allen, 18 September 2024; Lucy Lines, 18 September 2024; Submissions: 2, 3, 6, 7, 83.

[21] See for example Committee Hansards: Deanna Flynn-Wallis, 19 June 2024; Amy Aikman, 10 July 2024; Stacey Seedon, 18 September 2024; Submissions: 6, 50, 58, 63, 72

[22] Submission 58, p. 1.

> It was at around 29, when my last baby was around a year old, that my pain returned and brought new symptoms with it. Pain with bowel movements, and excruciating pain passing wind. This was predominantly during my periods. After some research into why this was happening, I came across others who had similar experiences, and women who mentioned it being connected to endometriosis.[23]

Endometriosis has no cure[24] but treatment and management options are available to address the symptoms of the disease. The treatment and management options include analgesics, hormonal and non-hormonal treatments, specific surgeries, or a combination of these treatments. Apart from these treatment and management recourses, as a chronic pain disease, several and varied support mechanisms are also accessible to individuals with endometriosis. Section 8 further discusses these treatment and management options and support systems.

In brief, endometriosis is a common inflammatory condition affecting girls, women and AFAB, where cells or tissues similar to the lining of the uterus grow outside it and become inflamed during menstrual periods. In other cases, endometriosis can be found in the bladder or the bowel. The presence of these endometrial-like cells outside of the uterine cavity often causes severe period and pelvic pain, fatigue, and infertility. The cure and cause of endometriosis is still largely unknown, but treatment and management options are available.

5.2. Prevalence of endometriosis in South Australia

The prevalence of endometriosis in Australia is increasingly noted given the increase in the number of individuals diagnosed with the condition. As of December 2023, the Australian Longitudinal Study on Women's Health (ALSWH) estimated that:

- 'around 1 in 7 (14%) women born in 1973–78 was estimated to have been diagnosed with endometriosis by age 44–49; and
- by age 31, a higher proportion of women in the younger cohort had been diagnosed with endometriosis (9.2% of those born in 1989–95 compared with 6.9% born in 1973–78).'[25]

The ALSWH explains that the increase in the cumulative incidence of endometriosis might be due to a growing awareness of endometriosis among this cohort, the public, and health professionals.[26] These figures, however, should be interpreted as approximations given the diagnostic delays of endometriosis, and that official diagnosis involves surgery and histological confirmation that could influence the prevalence of disease in the state.[27]

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[23] Submission 63, no page numbers.

[24] CHM Ng, et al., Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper; R O'Hara, H Rowe and J Fisher, 'Self-management in condition-specific health: a systematic review of the evidence among women diagnosed with endometriosis', *BMC women's health*, 2019 19(80): 1-19, doi: 10.1186/s12905-019-0774-6; R O'Hara, H Rowe and J Fisher, 'Self-management factors associated with quality of life among women with endometriosis: a cross-sectional Australian survey', *Human Reproduction*, 2021, 36(3): 647-655, doi: 10.1093/humrep/deaa330.

[25] AIHW, *Endometriosis.*

[26] AIHW, *Endometriosis.*

[27] IJ Rowlands, JA Abbott, GW Montgomery, R Hockey, P Rogers and GD Mishra, 'Prevalence and incidence of endometriosis in Australian women: a data linkage cohort study', *BJOG: An International Journal of Obstetrics & Gynaecology*, 2021, 128(4): 657-665, doi: 10.1111/1471-0528.16447.

The ALSWH further notes that approximately 7.6% of the cohort who were diagnosed with endometriosis by age 44-49, were surgically confirmed, and 6.6% was clinically suspected to have the disease. For a younger group of women and AFAB born in 1989-95, 'an estimated 3.8% [had] surgically confirmed endometriosis and 5.0% with clinically suspected endometriosis' by age 26-31.[28] The ALSWH categorises those survey participants whose diagnosis is recorded in the Medicare Benefit Schedule (MBS) or hospital data as having surgically confirmed endometriosis. Survey participants 'who self-reported a diagnosis of endometriosis in the survey or who had only been prescribed a restricted medication for endometriosis based on Pharmaceutical Benefits Scheme (PBS) data,' were categorised as having clinically suspected endometriosis.[29]

The evidence presented to the committee articulates that the number of individuals with endometriosis in South Australia closely reflects that of the national figures.[30] In their presentation to the committee, Professor Louise Hull of the Robinson Research Institute stated that 'about one in nine women have it, so that is 35,000 women in South Australia.'[31] Additionally, in their own survey of female students, the submission from the Pelvic Pain Foundation of Australia (PPFA) outlined a breakdown of young women in South Australia who are experiencing period pain, pelvic pain and endometriosis:

- 52.1% of female students reported regular severe period pain, compared to 50.2% nationwide;
- 42.1% experienced bowel or bladder pain, compared to 42.3% nationwide;
- 48.8% are experiencing three or more days of pelvic pain or discomfort of any kind on average a month, compared to 47.5% nationwide; and
- 16.8% are experiencing six or more days of pelvic pain or discomfort of any kind on average a month, which is the same as nationwide.[32]

This breakdown, highlights that the young women who are experiencing, on average, six or more days of pelvic pain or discomfort of any kind a month 'are at high risk of additional pain conditions over their lifetime[33]. In PPFA's presentation to the committee, Professor Susan Evans underlines this finding in predicting who would be suffering from chronic pain in the future and whose lives would be substantially affected.

> … once you get to six to 10, 11 to 15 or even everyday pain, this is persistent pain. This involves muscle reactions and the central nervous system and the quicker you get onto this, the quicker they will be less of a problem for health budgets, employers, productivity, emergency department presentations, etc., let alone the impact on the person.[34]

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[28] AIHW, *Endometriosis.*.

[29] AIHW, *Endometriosis.*.

[30] See for example Committee Hansards: Chalmers, Jane, 10 April 2024; Robinson Research Institute, 15 May 2024; Adelaide Pelvic Pain Network, 10 July 2024; Submission: 46

[31] Committee Hansard: Robinson Research Institute (Professor Louise Hull), 15 May 2024, p. 36.

[32] Submission 43, no page numbers.

[33] Submission 43

[34] Committee Hansard: Pelvic Pain Foundation of Australia (PPFA) (Associate Professor Susan Evans), 5 June 2024, p. 56.

In terms of the onset of endometriosis and its actual diagnosis, evidence received by the committee from individuals who had or still have endometriosis reveal that seven and 34 were the youngest and oldest ages, respectively, when perceived symptoms of endometriosis were observed. The length of years to having a clinical diagnosis for the disease could not be determined for many of the individuals who made submissions to the committee. For submissions that indicated perceived onset of endometriosis symptoms and official diagnoses,[35] this cohort articulates it takes an average of 10 years for a proper diagnosis, with a few (3) diagnosed on the same year as seeking medical help,[36] and one diagnosed after 32 years.[37]

All in all, endometriosis is a common disease among people born female at birth, with 1 in 7 of those born between 1973–78 to have been diagnosed with endometriosis by age 44–49. Increase in reporting of the incidence of endometriosis in Australia is attributed to the increase in awareness of the condition, despite delays in official diagnosis and laparoscopy as the gold standard to confirm the presence of endometrial cells. While there is no official survey to account for the number of girls, women and those AFAB in South Australia who have endometriosis, evidence provided to the committee shows similarity to that of the national figures.

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[35] See for example Submissions: 9, 14, 18, 20, 21.
[36] Submissions: 18, 56, & 76.
[37] Submission 63

6. IMPACT OF ENDOMETRIOSIS

The effects of endometriosis on the lives of individuals who suffer from disease vary and are multi-faceted. Individuals who have endometriosis do not necessarily have the same symptoms or experience similar severity in symptoms.[1] To some extent, an individual 'can have the symptoms without having endometriosis.'[2] Conversely, individuals can have endometriosis and not have any symptoms.

Coinciding with related literature,[3] the evidence given to the committee indicates that endometriosis also has negative direct and indirect impacts on the personal and social aspects of the lives of those with the condition.

6.1 Effects on individuals

Physical activities

Engaging in physical activities, such as exercise and sports, is challenging for persons with endometriosis. As one of the symptoms of endometriosis is fatigue, individuals with the disease can be exhausted every time they are going through it, depriving them of the ability to engage in day-to-day activities and activities that are physically demanding.[4]

> I was sporty. I loved playing soccer, swimming, running, doing high jumps and hurdles. Additionally, I loved the performing arts, singing, acting and even debating. I faced recurrent episodes of debilitating pain and distressing symptoms, resulting in me losing the energy to partake in sports[5]
>
> Now it has been well over a year since my diagnosis and my condition has gotten significantly worse and has turned chronic. I am now unable to exercise in any way, shape or form, even walking for a simple 5 minutes sends me into a flare up, this has caused my insulin to go up and be at risk of diabetes. I now have a fear of exercising as I am terrified of the pain that is to come afterwards.[6]

Evidence received by the committee also indicated that having a 'flare up' or heavy bleeding is considered an embarrassing situation, hence persons with endometriosis hesitate to do

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[1] J Frayne, T Milroy, M Simonis and A Lam, 'Challenges in diagnosing and managing endometriosis in general practice: A Western Australian qualitative study'. *Australian Journal of General Practice,* 2023, 52(8): 547-555, doi: 10.31128/AJGP-10-22-6579; M van der Zanden and AW Nap, 'Knowledge of, and treatment strategies for, endometriosis among general practitioners', *Reproductive biomedicine online*, 2016, 3(5): 527-31, 10.1016/j.rbmo.2016.02.003; Also see Committee Hansards: PPFA (Associate Professor Susan Evans), 5 June 2024; Berri Hearing (Elizabeth Eske), 12 June 2024; Submissions: 73, 83.

[2] Committee Hansard: PPFA (Associate Professor Susan Evans), 5 June 2024, p. 55.

[3] See for example: J Sinclair, CA Smith, J Abbott, KJ Chalmers, DW Pate and M Armour, 'Cannabis use, a self-management strategy among Australian women with endometriosis: results from a national online survey', *Journal of Obstetrics and Gynaecology Canada,* 2020, 42(3): 256-261, doi: 10.1016/j.jogc.2019.08.033; R O'Hara, H Rowe and J Fisher, 'Self-management factors associated with quality of life among women with endometriosis: a cross-sectional Australian survey; RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis.*

[4] See for example Committee Hansard: Berri Hearing (Julie Ahrens), 12 June 2024; Submissions: 6, 23.

[5] Committee Hansard Deanna Flynn Wallis, 19 June 2024, p. 126.

[6] Submission 29, p. 1.

physical activities.[7] In a submission, a mother shared the 'devastating look' on her daughter's face as she sees 'the blood run down the inside of her leg by half time of her game' of netball even if she had put on a fresh sanitary pad before the game.[8]

Emotional and mental health

Related literature on the impact of endometriosis emphasises its detrimental effects to a person's emotional and mental wellbeing,[9] especially for those with delayed diagnoses. The evidence given to the committee by individuals and parents of young people with endometriosis supports these findings.[10] For example, Ms Pfitzner expressed that with her financial constraints, after undergoing many surgeries, her mental health declined because of being 'bed bound due to pain which results in high anxiety but also stress', [11] as she struggles to return to work. Ms Pfitzner also mentioned social embarrassment whenever she gets heavy periods without warning and when she is 'not able to parent to the level that makes me feel like an adequate parent,'[12] as adding to her mental stress.

Medical procedures to diagnose, treat and manage endometriosis can also be emotionally and mentally taxing to sufferers of the disease.[13] For instance with laparoscopy (discussed further in Section 8), the emotional stress originates from repeated surgeries due to the recurrence of endometrial-like cells.

> I know, for so many who are at the beginning stages of this process, it is quite emotionally taxing knowing that laparoscopies might not necessarily last very long and that's the case for [the] friend I mentioned who has also had horrific experiences at Mount Barker hospital ... Because I have been going through this now for so long, I am so used to it, but in my earlier stages it was really quite emotionally taxing.[14]

Psychological stress or trauma can happen to individuals with endometriosis from unpleasant or stressful encounters with medical professionals during the diagnosis, treatment, and management phases.[15] The evidence given to the committee suggests that young people are more likely to experience this trauma given their lack of information and understanding of endometriosis when consulting with clinicians.[16] For instance, a mother of someone who has endometriosis related how her daughter continues to be traumatised from a endometriosis-

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[7] See for example Committee Hansard: Berri Hearing (Jesse Lang), 12 June 2024; Submissions: 6, 29.

[8] Submission 6, p. 2.

[9] J Sinclair, et al., 'Cannabis use, a self-management strategy among Australian women with endometriosis: results from a national online survey, p. 257; F Facchin, B Giussy, E Saita, P Mosconi, A Roberto, L Fedele, and P Vercellini, 'Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference', *Journal of Psychosomatic Obstetrics & Gynecology*, 2015, 36(4): 135-141, doi: 10.3109/0167482X.2015.1074173.

[10] Committee Hansards: Berri Hearing (Jule Ahrens, Jenny Han, Jesse Lang,
Kaye Schober, Amara Turner), 12 June 2024; Amy Aikman, 10 July 2024; Submissions: 23

[11] Submission 23

[12] Submission 23, p. 1.

[13] Committee Hansards: Berri Hearing (Jule Ahrens, Jenny Han, Jesse Lang,
Kaye Schober, Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Rochana Watkins, 10 July 2024; Amy Aikman, 10 July 2024.

[14] Committee Hansard Christie Nancarrow, 19 June 2024, p. 131.

[15] Committee Hansards: Berri Hearing (Julie Ahrens, Jenny Han, Jesse Lang,
Kaye Schober, Amara Turner), 12 June 2024; Commissioner for Children and Young People, 10 July 2024.

[16] Committee Hansards: Berri Hearing (Julie Ahrens, Jenny Han, Jesse Lang,
Kaye Schober, Amara Turner), 12 June 2024.

related consultation her daughter had when she was 16 years old. Her daughter described that the clinician asked, 'really inappropriate questions such as: had she had anal or oral sex, was she with a partner and had she been promiscuous?'[17] Section 9 discusses distressing experiences with those in the medical profession as one barrier to accessing diagnosis, treatment, and management of endometriosis.

Additionally, the anticipation of pain and somehow normalising it negatively impacts the mental health of individuals with endometriosis.[18] The evidence made to the committee states that women are putting up with the pain from endometriosis as those around them, including clinicians, dismiss the symptoms, leading to the normalisation of pain.[19]

Infertility

Endometriosis can cause infertility in women or those AFAB.[20] For example, in separate presentations to the committee, Associate Professor George Condous[21] and Lucy Lines[22] indicated that ovarian endometriosis impacts fertility. Ovarian endometriosis is when cysts are formed in the ovaries causing a 'reduction in ovarian volume/reserve by compression from the expanding cyst, pelvic inflammation/local adhesion formation surrounding the ovary (and other pelvic organs, and associated blockage of fallopian tubes (often in association with the endometrioma cysts).'[23] Ms Lines also explained that the presence of endometriosis outside the fallopian tubes and the 'whole general body inflammation' that could occur in individuals with endometriosis, can also impact fertility.[24]

> For those who explicitly desire to have children, endometriosis-induced infertility takes a toil in their mental health.[25]
>
> Endometriosis has an impact on the people and partners of those living with the illness as they watch a loved one suffer and be inactive due to pain. Struggles with infertility has a huge emotional impact on partners too.[26]

The evidence given to the committee shows the concerning impact of the disease to fertility, despite that not all women are that concern about it.[27] However, the submission from Ms Sandhu implies that the impact of endometriosis on fertility, 'that this disease can take away your choice.'[28]

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[17] Committee Hansard Berri hearing (Julie Ahrens), 12 June 2024, p. 80.

[18] See for example Committee Hansard: Dr Jane Chalmers, 10 April 2024.

[19] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Submission: 9.

[20] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Submissions: 1, 7, 20, 31

[21] Committee Hansard: Adelaide Pelvic Pain Network, 10 July 2024.

[22] Committee Hansard: Elosie Zanoni, 18 September 2024.

[23] Endo Health, *Ovarian Endometriosis*, Endo Health website, 2024, accessed 31 December 2024.

[24] Committee Hansard: Elosie Zanoni, 18 September 2024, p. 282.

[25] See for example Committee Hansards: Berri hearing (Julie Ahrens), 12 June 2024; Christie Nancarrow, 19 June 2024; Professor Jason Abbott, 11 September 2024; Submissions: 7, 31.

[26] Submission 7, no page numbers.

[27] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024.

[28] Submission 20, no page numbers.

Education

Endometriosis can negatively affect school or university attendance and participation. The evidence made to the committee indicates that for young people who experience abdominal or period pain, and especially if accompanied by heavy bleeding, may not be able to attend school or university.[29]

> … I had excruciating abdominal pain, and my bleeding was so heavy that I went through multiple “overnight” pads throughout the day. With each period, I would miss at least three days of school, just to roll around in bed in tears and scorch my skin with an overheated wheat bag…[30]
>
> As a teenager I had painful periods and severe cramps which meant skipping school or university for the first one to two days of the period, lying in bed at home with a hot water bottle and taking Panadol or Naprogesic medication.[31]

Endometriosis can also hinder an individual from completing an academic degree. Some evidence submitted to the committee noted of people with endometriosis were unable to continue with their university degrees.[32] In his presentation to the committee, Mr Watkins shared that his partner, Ms Watkins, missed out on getting a degree in nursing because her body could not manage it, given the debilitating effect of endometriosis.

> Rochana actually wanted to help people, she wanted to be a nurse and actually tried to study multiple times and each time due to flare ups or due to ongoing appointments or hospital visits it just became difficult. She had to keep withdrawing more and more from the courses and in the end sort of gave up on that dream.[33]

Attendance and participation in school or university activities are also difficult as not everyone, including peers, are necessarily aware or know what endometriosis is and its impact on the person experiencing it.[34]

> … my journey with [e]ndometriosis started when I was 8 years old when I had my first period. Primary school was very difficult as I couldn’t talk with friends as they were too young at the time and I was going through heavy, sometimes having weeks with a period. I started to get bullied because I had many days off school, or I couldn’t keep up with sports or just play games at recess or lunch.[35]
>
> I was turning down invitations from my friends out of fear that I would flare up and need to go home or that I would not be energised enough to present to them as the funny, outgoing person I wanted them to see.[36]

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[29] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Berri hearing (Julie Ahrens, Jenny Han, Jesse Lang, Kaye Schober, Amara Turner), 12 June 2024; Submissions: 3, 7, 14

[30] Submission 71, p. 1.

[31] Submission 7, no page numbers.

[32] See for example Committee Hansard: Associate Professor George Condous, 10 July 2024; Submission: 12

[33] Committee Hansard: Shannon Watkins, 10 July 2024, p. 163.

[34] See for example Committee Hansard: Georgia Gosse, 10 July 2024; Submission: 44.

[35] Submission 21, no page numbers.

[36] Committee Hansard: Dr Monique Kanters, 18 September 2024, p. 266.

To some extent young people with endometriosis feel alone or isolated.[37] The evidence presented to the committee noted that as young people's school or university attendance and participation in activities is hampered, their overall wellbeing is affected.[38]

> We also noted that [for] a lot of either us or our friends who have endo or other pelvic pain conditions, it really does impact how we can engage with the things around us: sports, education, [and] all those extra curriculars [that] are really foundational to wellbeing, especially of young people as we are making our place in the world…[39]
>
> Starting periods can be a scary experience at the best of times, without adding on the trauma of severe pain, heavy bleeding and worrying about bleeding through your clothing in public. None of her friends were going through this, so she felt very alone… [40]

Finances

The adverse impact of endometriosis on an individual or a family's financial resources cannot be overstated.[41] The evidence provided to the committee notes that endometriosis creates financial burdens in terms of securing private health insurance coverage,[42] fees for fertility treatment,[43] out-of-pocket costs for surgeries,[44] specialists,[45] medications,[46] imaging,[47] and accessing allied health services.[48] The cost is even exacerbated for those who live in regional and rural areas if they travel to Adelaide or interstate to seek medical services. In her submission, Ms Hand emphasised the financial challenge to get diagnosed via laparoscopy for someone who lives in the Riverland.

> Sadly, accessing this surgery is a major hurdle that many face across the state and certainly those based regionally would be required to travel to metropolitan Adelaide to seek specialised help. The costs involved with travelling only add to the already exorbitant costs of medical appointments and procedures.[49]

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[37] See for example Committee Hansard: Associate Professor George Condous, 10 July 2024; Submissions: 14, 51.

[38] See for example Committee Hansards: Georgia Gosse, 10 July 2024; Submissions: 6, 14.

[39] Committee Hansard: Commissioner for Children and Young People (Valeria Caceres-Galvez), 10 July 2024, p. 187.

[40] Submission 51, p. 1.

[41] M Armour, JC Avery, M Leonardi, L Van Niekerk, ML Druitt, MA Parker, JE Girling, B McKinnon, A Mikocka-Walus, CH Ng and R O'Hara, 'Lessons from implementing the Australian national action plan for endometriosis', *Reproduction and Fertility*, 2022, 3(3), pp.C29-C39, doi: 10.1530/RAF-22-0003.

[42] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Berri hearing (Kaye Schober), 12 June 2024; Commissioner for Children and Young People, 10 July 2024; Submissions: 23, 59

[43] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Thrive Family Practice, 28 August 2024; Submissions: 23.

[44] See for example Committee Hansard: Thrive Family Practice, 28 August 2024; Submissions: 23

[45] See for example Committee Hansard: Berri hearing (Jesse Lang), 12 June 2024; Submissions: 2, 6, 9, 14, 23.

[46] See for example Committee Hansards: Berri hearing (Dr Nasser Shehata), 12 June 2024; Thrive Family Practice, 28 August 2024; Submissions: 23, 14, 54

[47] See for example Committee Hansards: Berri hearing (Jesse Lang), 12 June 2024, Commissioner for Children and Young People, 10 July 2024; Submission: 4

[48] See for example Committee Hansards: Berri hearing (Kaye Schober, Jesse Lang), 12 June 2024; Adelaide Pelvic Pain Network, 10 July 2024; Commissioner for Children and Young People, 10 July 2024; Submission: 23

[49] Submission 60, p. 7

The evidence received by the committee also implies that the numerous expenses associated with endometriosis is largely due to the need for those with the condition to seek diagnosis, treatment and management, but often not receiving accurate and/or appropriate care.[50]

> I have sought traditional and non-traditional methods to alleviate symptoms, trying to establish the root cause of my health ailments. I have spent thousands and thousands of dollars in the hope that something may help to make me feel well.[51]
>
> I think out of all of the issues (apart from the pain) the biggest issue is medical costs. These just go on and on as you try to find a way of easing the pain.[52]

For young people who experienced endometriosis-related symptoms, parents often take care of the majority of the expenses.[53] The evidence provided to the committee underlines greater expenses for families who have to bring their daughters to Adelaide for treatment and management.[54] It can be said that getting clinical validation for an individual's experience of endometriosis-related symptoms is costly with expenses considered to be getting 'harder each time.'[55]

Personal and social relations

Endometriosis negatively affects personal and social relations.[56] The evidence presented to the committee indicates the strain on or loss of relationships between individuals with endometriosis and their families and friends.[57] One of the factors contributing to the tension in relationships is the lack of knowledge and understanding of personal relations of what a person with endometriosis is going through.[58] In her submission to the committee, Ms Wurfel, stated that amidst her suffering from severe pain and frequenting hospitals to get care, she also had to endure the 'weight of being misunderstood' by her 'own family, who at times doubted the validity of my suffering'.[59]

As noted earlier, given the physical and psychological effects of endometriosis to people who have it, the latter often limit their participation in social gatherings with families and friends, that could potentially strain personal relationships.[60] For example, in her presentation to the committee, Ms Savage said that she turned down invitations from her friends because of fear

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[50] See for example Committee Hansard: Berri hearing (Jesse Lang, Kaye Schober, Amara Turner); Submissions: 2, 6

[51] Committee Hansard: Berri hearing (Jesse Lang), 12 June 2024. p. 104.

[52] Submission 2, p. 2

[53] See for example Submissions: 14, 20.

[54] See for example Committee Hansard: Dr Monique Kanters, 18 September 2024.

[55] Submission 14, p 2.

[56] See for example Committee Hansard: Robinson Research Institute, 15 May 2024; Submissions: 20; 42, 74.

[57] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; Endometriosis Australia, 30 October 2024; Submissions: 20, 62, 83.

[58] See for example Committee Hansards: Robinson Research Institute, 15 May 202; Pelvic Pain Foundation of Australia, 5 June 2024; Georgia Gosse, 10 July 2024; Submissions: 2, 70, 74, 83.

[59] Submission 74, p. 1.

[60] See for example Committee Hansards: Berri hearing (Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Dr Monique Kanters, 18 September 2024; Submission: 77.

of having a flare up and not being able to ‘present to them as the funny, outgoing person I wanted them to see.’[61]

Some evidence received by the committee also noted that individuals with endometriosis felt a ‘burden’ to their families.[62] In her submission to the committee, Ms Holbrook shared that the unpredictability of the severity of endometriosis makes ‘you feel a burden on your partner not being 100% yourself all the time.’[63]

Overall wellbeing and life trajectory

The evidence discussed above confirms previous studies about endometriosis’ negative impact beyond a person’s physical body.[64] For young people, the evidence given to the committee indicates impairment in their sense of self or identity as interactions essential to their personal development, such as education, social and sport interactions are limited, when they experience pain on a regular basis. For example, Ms Hudson recalls how endometriosis-related symptoms, that became severe in her teens, affected her development as a young person, having menarche at age 11.

> These symptoms became so severe in my teens that I could only attend school 4 days out of an entire term in year 10. The negative impacts these symptoms and isolation caused during this important developmental period of sense-of-self and identity lead to confusion, self-loathing and disconnection from myself and the world around me.[65]

Ms Savage from Mount Gambier also articulated her ‘disappointment’ over the person she has become, expressing that with endometriosis, the person that she became ‘was a version of myself I didn't even recognise.’[66]

In their presentation to the committee, Professor Hull of the Robinson Research Institute elaborates how endometriosis not only affects a young person’s overall wellbeing, but also their life trajectories. Professor Hull explained how personal relations and education facilitate young people’s progression in life, that if negatively affected, will have a significant impact on young people’s futures.

> … if you are not at school, everyone else goes to the party on the weekend and you don't, and you go back to school and you are a stranger in the classroom and you've got behind on everything, so now you have to find someone who will help you catch up and you have lost your social connections as well as your education.

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[61] Committee Hansard: Dr Monique Kanters, 18 September 2024, p. 266.

[62] See for example Committee Hansard: Berri hearing (Jesse Lang, Kaye Schober), 12 June 2024; Submissions: 9.

[63] Submission: 9, p. 2

[64] See for example R O’Hara, et al., ‘Self-management factors associated with quality of life among women with endometriosis: a cross-sectional Australian survey’; Also see Committee Hansards: Robinson Research Institute, 15 May 2024; Dr Monique Kanters, 18 September 2024; Submissions: 8, 14.

[65] Submission 14, p. 1.

[66] Committee Hansard: Dr Monique Kanters, 18 September 2024, p. 266

> How do you get a good job? And then you don't get a great job that you like [,]… you lose confidence totally and people don't want to get up in the morning.[67]

Professor Hull's statement is validated in the testimony below, where there is expressed fear over the impact of endometriosis on their future and the disease's effect on an individual's sense of accomplishment.

> … I am too scared to plan things for my future in fear the hospital will call me with a moment's notice to be seen - the future impact on this on my career, my future family, and my current family, is frightening.[68]

The impact of endometriosis on a person's identity and self-worth is also underlined in the evidence received by the committee.[69] The evidence reveals how the disease takes away those essential things that contribute to people's sense of self and meaning. In her presentation to the committee, Ms Aikman concluded her speech by stressing how having endometriosis made her feel inconsistent and unreliable, while Mr Watkins expressed the major changes he observed in his partner for having endometriosis for a long time.

> … I have always been someone who has wanted to be consistent, and I have had hobbies, a lot of hobbies, in my life … Endometriosis … I felt, stopped me from doing so many things and made me quite unreliable and inconsistent when it came to actually getting out there and being able to commit to certain training and commit to certain hobbies.[70]
>
> Rochana was a bubbly, bright person. She had dreams and ambitions. She is now a shadow of herself, not even a glimpse of the person that she used to be.[71]

As can be seen, endometriosis affects an individual's quality of life,[72] given its consequences to their overall wellbeing and development.

Generally speaking, individuals with endometriosis suffer more than just chronic period or pelvic pain or other physiological signs of the disease. Apart from the actual symptoms, endometriosis affects a person's physical and psychological make-up that impedes their education or work. A woman's or AFAB's fertility is also affected and is devastating for people who look forward to having children. Seeking diagnosis, treatment and management for endometriosis is costly, adding a further challenge to a stressed out individual. Accordingly, persons with endometriosis have unstable wellbeing and problematic life trajectories.

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[67] Committee Hansard: Robinson Research Institute (Professor Louise Hull), 15 May 2024, p. 51.

[68] Submission: 8, p. 2.

[69] See for example Committee Hansards: Associate Professor George Condous, 10 July 2024, Rochana and Shannon Watkins, 10 July 2024; Submission: 2.

[70] Committee Hansard: Amy Aikman, 10 July 2024, p. 174.

[71] Committee Hansard: Shannon Watkins, 10 July 2024, p. 163.

[72] See for example Committee Hansards: Sonography (Professor Nayana Parange), Robinson Research Institute (Professor Louise Hull); Submissions: 2, 3.

6.2 Society

Given the prevalence of endometriosis in Australia, it is notable from the evidence presented to the committee that the effects of endometriosis go beyond just the individual. The personal and social challenges experienced by people with endometriosis generally affects society in two ways – overburdening the healthcare system and hindering a person's full potential to contribute to their communities, consequently affecting the country's economy.

As noted earlier, individuals with endometriosis often avoid attending or participating in social activities within their families and communities due to common endometriosis-related symptoms such as period and/or pelvic pain, fatigue, and flare ups. Evidence provided to the committee articulates that disengagement from personal and social relations bars people from being productive and developing or maintaining connections.[73] The impact of endometriosis on productivity relative to paid work is discussed in Section 10.

A negative impact to the country's health system is through the expenses on hospitalisations, presentations to emergency department, and private hospital services. In their presentation to the committee, Lisa Schofield, one of the representatives from the Australian Government Department of Health and Aged Care (DHAC), reported that the 'Australian Disease Expenditure Study estimated that '$247.2 million was spent on endometriosis in the Australian health system in 2020-21, of which, 86 per cent was attributed to hospitals, admitted patients, outpatients, emergency department and private hospital services.'[74] According to the Australian Institute of Health and Welfare (AIHW), the amounts reported in the study incorporates payments from 'Australian and State and Territory Governments, Private Health Insurance, and out of pocket payments by patients.'[75] Nevertheless, AIHW noted that these expenses might be underestimated 'where data are lacking on endometriosis-related services, such as primary care services and medicines.'[76]

Another negative outcome of endometriosis to the health system is the additional strain it brings to a workforce that suffers from skills shortage, especially in regional areas.[77] As the number of individuals with the condition continuously seek diagnosis, treatment, and management, mostly in the public health system, the limited health and medical experts on pelvic or women's health not only creates challenges to accessing these professionals, but also subjects them to burnout.[78]

Furthermore, the debilitating impact of endometriosis on people who have it causes reduced or loss of productivity. Relevant literature indicates that the significant cost of illness burden of endometriosis amounts to 'over $9.7 billion per year for Australia,'[79] where '75-84% of this

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[73] See for example Committee Hansard: Berri Hearing (Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Submissions: 7, 8.

[74] Committee Hansard: Stacey Seedon, 18 September 2024, p. 306

[75] AIHW, *Endometriosis, Economic burden*. AIHW website, 2023, accessed 06 January 2024.

[76] AIHW, *Endometriosis, Economic burden*.

[77] See for example Committee Hansards: RANZCOG, 10 July 2024; Dr Alex Liew, 11 September 2024: Submission: 4.

[78] See for example Committee Hansards: SHINE SA, 10 July 2024; Dr Alex Liew, 11 September 2024; Submission: 30.

[79] N Giese, E Gilbert, A Hawkey and M Armour, 'Unmet Needs of Australians in Endometriosis Research: A Qualitative Study of Research Priorities, Drivers, and Barriers to Participation in People with Endometriosis', p. 2.

cost is due to productivity loss.'[80] Productivity loss is brought about by either absenteeism and/or presenteeism or less productivity while at work.[81] In their presentation to the committee, Lisa Schofield, of DHAC, said that the Australian Disease Expenditure Study estimated that on a yearly basis, the overall cost of endometriosis in Australia… is about $30,900 per person with the condition.'[82] This amount includes '$25,800 from lost productivity, $3,900 for health costs and about $1,100 carer costs.'[83]

Hence, addressing early endometriosis-related symptoms or preventing the level where individuals experience every day or persistent pain is essential to addressing the impact of the disease to a nation's economy and health system. As Associate Professor Susan Evans stated during the PPFA's presentation to the committee, 'the quicker you get onto this, the quicker there will be less of a problem for health budgets, employers, productivity, emergency department presentations, etc., let alone the impact on the person.'[84] The submission from Queensland Endo (QENDO) also emphasised the far-reaching impacts of endometriosis to 'families, workplaces, and communities,' that if untreated or poorly managed' will cause 'strained relationships, decreased productivity in the workforce, and increased healthcare costs.'[85]

As shown above, the negative effects of endometriosis on individuals' personal and social lives have ripple effects on a country's health expenditures and economy. The frequent hospitalisations and emergency department presentations, among others, and the exhaustion of limited women's health and pelvic pain specialists impacts the country's health system, while productivity loss through absenteeism and presenteeism affecting the workforce have negative outcomes on the economy.

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[80] M Armour, K Lawson, A Wood, CA Smith, J Abbott, 'The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey', *PLoS ONE 14*, 2019, (10): e0223316, doi: 10.1371/journal.pone.0223316, p. 1

[81] Armour, Mike, et al. "Endometriosis and the workplace: Lessons from Australia's response to COVID-19." *Australian and New Zealand Journal of Obstetrics and Gynaecology* 62.1 (2022): 164-167.

[82] Committee Hansard: Stacey Seedon, 18 September 2024, p. 306

[83] Committee Hansard: Stacey Seedon, 18 September 2024, p. 306

[84] Committee Hansard: Pelvic Pain Foundation of Australia (Associate Professor Susan Evans), 5 June 2024, p. 56.

[85] Submission 16, p. 7.

7. ACTIONS PLANS AND GUIDELINES

Given the complexity of endometriosis, its prevalence in Australia, and its associated negative individual and societal impacts, actionable steps addressing the challenges in the diagnosis, treatment, and management of endometriosis is imperative. Australia leads in this area with the crafting of a 'roadmap and blueprint to tackle endometriosis in a nationwide, coordinated manner.'[1] Existing national treatment and management plans and a recent international guideline on endometriosis also provide additional information and strategies towards the diagnosis, treatment, and management of the disease.

7.1 The National Action Plan for Endometriosis

The National Action Plan for Endometriosis (NAPE) is a major milestone to holistically address endometriosis in Australia. Released in July 2018, the NAPE aims to tackle endometriosis in a multi-pronged approach through three priority areas - awareness and education, clinical management and care, and research.[2]

Under Priority 1 – awareness and education, the NAPE considers it important that timely education about and increased awareness of endometriosis are delivered to patients, health and medical professionals, and the general public, such as communities, schools and workplaces. Accordingly, this would create a more nuanced understanding of endometriosis as a chronic pain condition with multiple effects on girls, women, and those AFAB, that in turn, has consequences to society's economic and health systems. Actions focused on awareness and education will clarify the treatment and management pathways and resources to support people with endometriosis and their families and/or carers.

A major program under Priority 1 is PPFA's Periods, Pain and Endometriosis Program (PPEP) Talk®. PPFA is a national not-for-profit organisation, based in Adelaide that is 'Australia's premier organisation facilitating practitioner and patient education in Endometriosis and Pelvic Pain.'[3] PPEP Talk® is PPFA's signature school program, developed and launched in South Australia in 2019, to 'deliver contents about menstrual periods and what constitutes 'normal'.'[4] The Australian Government DHAC has committed $5 million (from 2021-22 to 2025-25) to PPEP Talk® for its continuation and expansion in schools. In South Australia, the Department for Education and SA Health also provide funding to the program. Details on PPFA's PPEP Talk® and other education programs are detailed in Section 11.

Furthermore, through the *Increasing Awareness of Endometriosis in Priority Populations Grant* of the Commonwealth Government, about $2 million was awarded to three organisations to further work on the following areas:

- drive improvements and support in the endometriosis community (Australian Coalition for Endometriosis);[5]

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[1] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. C30.

[2] Commonwealth of Australia, *National Action Plan for Endometriosis*, Department of Health, 2018, p. 9.

[3] Submission 43, no page numbers.

[4] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. C35.

[5] Department of Health and Aged Care, *Record action on endometriosis continues in 2024* [media release], Ministers DHAC, 18 January 2024, accessed 16 March 2024.

- develop and implement a Workplace Assistance Program to support employees and employers[6] and reach priority groups with accessible and fit for purpose resources so all Australians can be better supported to live with endometriosis (Endometriosis Australia); and
- develop a national endometriosis mentor program to support those newly diagnosed with endometriosis (QENDO Inc).[7]

The priority on clinical management and care (Priority 2) in the NAPE is intended to achieve three things:

- support healthcare professionals provide a 'best-practice, nationally consistent clinical management and care'[8] to individuals with endometriosis;
- reduce delays in the care pathways through 'early access to endometriosis specific education, diagnosis, intervention, fertility treatment, pain management options and providers of choice'; and
- make affordable and accessible multiple care options to patients, 'including vulnerable populations,' for a robust clinical delivery.[9]

The Endometriosis Clinical Practice Guideline (2021) and the Raising Awareness Tool for Endometriosis (RATE) developed by The Royal Australian and New Zealand College of Obstetricians and Gynaecologist (RANZCOG) were initial efforts under Priority 2. RATE is an online resource for consumers to facilitate health providers and patients' discussions about endometriosis associated symptoms.

In the Endometriosis Progress Report, the 2022-23 endometriosis support Budget measures relevant to Priority 2 of the NAPE included:

- 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;
- 22 specialised Endometriosis and Pelvic Pain GP clinics across Australia;
- development of an Endometriosis Management Plan to support patients in primary care, including in the Endometriosis and Pelvic Pain clinics;
- development and promotion of an Endometriosis Living Guideline to support new and ongoing research into the diagnosis and management of endometriosis; and
- improvement of the utilisation of existing Medicare Benefits Schedule and Pharmaceutical Benefits Scheme items through ongoing review and promotion of available treatments for endometriosis.[10]

Research as Priority 3 of the NAPE acknowledges the capacity of Australia to lead and develop research on endometriosis, given 'the strength, collaborative will and specialised

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[6] Commonwealth Government, *Endometriosis Progress Report 2024 Update,* Department of Health and Aged Care (DHAC), 2024, p. 5.

[7] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 5.

[8] Commonwealth of Australia, *National Action Plan for Endometriosis*, p. 7.

[9] Commonwealth of Australia, *National Action Plan for Endometriosis*, p. 7.

[10] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 2.

knowledge of its research community.'[11] Through funding and support, research on endometriosis is hoped to 'pave the way for the prevention and the development of a cure.'[12] The National Endometriosis Clinical and Scientific Trials (NECST) Network is one of the NAPE's first initiatives to boost research on endometriosis in Australia. Funded through the Medical Research Future Fund (MRFF), the network aimed at identifying knowledge gaps regarding endometriosis is composed of advocates, health and medical professionals, and researchers, that reflects an inter- and multidisciplinary approach to studying the disease.

Other than the NECST, the MRFF 'has invested $19.11 million in 11 grants with a focus on endometriosis, since its inception in 2015 to 31 January 2024.'[13] It has funded research looking into awareness, diagnosis, and treatment of endometriosis among children and young people, alternative options to treatment and management, initiatives to hasten diagnosis, such as imaging, fertility, and designing a care approach. Additionally, the National Health and Medical Research Council has awarded research grants to endometriosis related research.[14] $1.4 million has been allocated to EndoZone, a digital platform, to continuously provide evidence-based information on endometriosis.

As a product of the collaborative efforts and advocacies of 'patient advocates, parliamentarians, clinicians, researchers, and women's health organisations,'[15] the NAPE benefits not only the individuals with endometriosis, but also, families, carers, and health and medical professionals. This is because improved outcomes such as 'greater awareness and education, improved access to services that are appropriate, available, and accessible, and support for further research relevant to need'[16] are developed and put in place.

7.2 Chronic disease and management plan

As endometriosis is a chronic disease, persons with endometriosis may be able to access a chronic disease management plan. A chronic disease management plan is a GP-led plan that coordinates and facilitates the health and medical providers and services of the patient, including limited access to allied health practitioners. The chronic disease management plan helps in the coordination of care for people with chronic ailments in terms of accessing 'appropriate assessment and services.'[17] Included in this chronic disease care plan is the 'access to up to five Medicare-subsidised visits to a range of allied health services (for example physiotherapy, psychology, dietician).'[18] The chronic disease management plan, a multidisciplinary framework of care, is led by a general practitioner (GP) and is considered 'perfectly reasonable' in consideration of the complexity of endometriosis and the high cost in securing treatment and management options.[19]

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[11] Commonwealth of Australia, *National Action Plan for Endometriosis*, p. 18.

[12] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 3.

[13] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 3.

[14] Commonwealth Government, *Endometriosis Progress Report 2024 Update.*

[15] University of New South Wales, *National Action Plan for Endometriosis (NAPE),* The NECST Network, no date, accessed 14 March 2024.

[16] Commonwealth of Australia, *National Action Plan for Endometriosis*, p. 3.

[17] RANZCOG, *Australian clinical practice guideline for the diagnosis and management of endometriosis*; Also see Submission: 52.

[18] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. 34; Also see Committee Hansards: Dr Alex Liew, 11 September 2024; Gayelene Allen, 18 September 2024; Submissions: 4, 38, 52.

[19] Committee Hansard: Professor Jason Abbott, 11 September 2024, p. 241; Also see Committee Hansards: Commissioner for Children and Young People, 10 July 2024; Dr Alex Liew, 11 September 2024; Submission 20.

While the chronic disease management plan is available, related literature and evidence presented to the committee indicates that the plan is either not widely accessed by those with endometriosis or is not known to the latter.[20] The evidence presented to the committee indicates the lack of awareness of the plan among clinicians and patients. Out of the 35 oral presentations and 85 submissions made to the committee, only 12 presentations and 15 submissions mentioned the plan. Of these, very few comments were made by individuals with endometriosis and the majority of comments were made by health and medical professionals.

In her presentation to the committee, Elizabeth Eske, a Physiotherapist at the Women's and Pelvic Health Physio in the Riverland, articulated that both women and GPs that she has worked with in the Riverland were unaware of the chronic disease management plan.

> Most of the women are not aware that they are eligible for these CDMPs… I did speak to a GP who I work with. GPs often have a bit of an incomplete understanding of these conditions—like I said, lack of knowledge—and that could be within their training, I am not 100 per cent sure. But that can be used for the GP management plan as well… I guess the GPs aren't aware that these women are eligible for these management plans…[21]

The lack of clarity on who is eligible for the chronic disease management plan is noted in the evidence provided to the committee as a reason for fewer access of the plan among persons with endometriosis.[22] Dr Irina Hollington’s submission also implies that as individual providers might not be co-located, the effectiveness of a chronic disease management plan might be reduced.[23]

In their presentation to the committee, representatives from DHAC were asked for statistics or information on the number of individuals who have a chronic disease management plan, including team care arrangements. The information DHAC provided to the committee after taking the question on notice, only showed an aggregated figure for all chronic conditions, not just for endometriosis, therefore making it hard to determine the actual number of individuals with endometriosis accessing a plan.

During the presentation, representatives from DHAC reported the changes that will be made to the chronic disease management plan in November 2024. These modifications, however, have been deferred to 1 July 2025 to have ample time for providers and practices to prepare and be ready for the changes. Asked what modifications were to be made to the chronic disease management plan during DHAC’s presentation to the committee, Imogen Colton, a Director of the Medicare Benefits and Digital Health Division, stated that the changes to be made were to simplify and streamline the process for health care professionals and patients in accessing and providing care, respectively, and not the forms of treatment.

> The changes that are due to come in are really changes to the GP items…The new plans are simplified and streamlined, essentially. We are modernising the

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[20] M Armour, et al., ‘Lessons from implementing the Australian national action plan for endometriosis; See for example Committee Hansards: Berri hearing (Elizabeth Eske), 12 June 2024; Gayelene Allen, 18 September 2024.

[21] Committee Hansard: Berri Hearing (Elizabeth Eske), 12 June 2024, p. 112.

[22] See for example Committee Hansard: Berri hearing (Elizabeth Eske), 12 June 2024; Submission 20.

[23] Submission: 52.

> process. The process has been in place for quite a long time. It is really around providing them with a more streamlined experience… the intent and types of treatment available will be unchanged.[24]

Whilst the chronic disease management plan may be an ‘untapped opportunity’ for people with endometriosis, its availability and the reported modification ‘might not remove the financial barrier to accessing affordable treatment for many.’[25] This is noted in Ms McDonald’s submission to the committee where she states,

> My initial appointment was $200, with a $50 private health rebate, for a 1-hour session. My next appointment was $120 with a $39 private health rebate, for a 30-minute session. I am aware that physiotherapy can be added to a Health Care plan with Medicare, and I did this with a previous therapist, however the gap was still similar, and I consider it far too high.[26]

This is further mentioned in RANZCOG’s presentation to the committee where Dr Waterfall said,

> … We have a clinic that is privately owned that sits next to the hospital, and the patients have to pay a gap, even if they have a GP chronic disease management plan for endometriosis, of which I am a signatory for so many. I feel like half the endo patients at the Adelaide Hills have me as a signatory to their current disease management plan to allow them to access physio, but it doesn't take much off the cost.[27]

As can be seen, individuals with endometriosis may access a chronic disease management plan through Medicare, as endometriosis is classified as a chronic disease. The oral presentations and submissions that mentioned chronic disease management plan imply it to be less helpful in containing endometriosis-related costs. Cost-related concerns might not be necessarily addressed soon by the chronic disease management plan despite upcoming changes as these do not include modifications in the ‘intent and types of treatment available’.[28]

7.3. European Society of Human Reproduction and Embryology (ESHRE) Guideline on Endometriosis

The ESHRE Guidelines for Endometriosis is another significant document in the diagnosis, treatment, and management of endometriosis. Published by the European Society of Human Reproduction and Embryology in 2005, the Guideline has been updated in 2007, 2014, and 2022 (the most recent). Overall, the ESHRE Guidelines for Endometriosis provides advice, in the form of recommendations, on how best to diagnose and managed endometriosis based on research evidence and considered opinion of the guideline’s development group.

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[24] Committee Hansard: Department of Health and Aged Care (DHAC) (Imogen Colton), 25 September 2024, p. 312.

[25] M Armour, et al., ‘Lessons from implementing the Australian national action plan for endometriosis, p. 34; Also see Committee Hansard: RANZCOG, 10 July 2024; Submissions: 36, 38, 70.

[26] Submission 36, no page numbers.

[27] Committee Hansard: RANZCOG (Dr Heather Waterfall), 10 July 2024, p. 219.

[28] Committee Hansard: DHAC (Imogen Colton), 25 September 2024, p. 312.

The recommendations in the 2022 version of the ESHRE Guidelines for Endometriosis is similar to that of RANZCOG-produced clinical guidelines.[29] The ESHRE Guidelines is highlighted in the evidence presented to the committee, especially by those from the health and medical arena, because of its recommendation of imaging as an additional and reliable tool to diagnose endometriosis, provided 'negative findings do not exclude [the] disease.'[30]

> … another very significant change was that the European Society of Human Reproduction and Embryology updated their guidelines in 2022 to for the first time suggest that ultrasound or MRIs could replace the need for laparoscopy for diagnosis of endometriosis if those modalities do show a positive, but they do have the caveat that a normal scan doesn't exclude endometriosis because of the limitations of not seeing superficial disease.[31]

In the previous versions of the Guidelines, keyhole surgery or laparoscopy with confirmation through histology or the microscopic examination of a tissue taken during biopsy, is the 'gold standard' to diagnosing endometriosis.[32] Associate Professor George Condous' presentation to the committee explained that laparoscopy was largely relied on for the diagnosis of endometriosis up until 2008 due to the limited diagnostic capability of a basic pelvic ultrasound in the past.[33] This rationale is supported in Amara Turner's and Gayelene Allen's experience with ultrasounds.

> I think that instead of just handing out a contraceptive all the time, that they need to be more willing to do the laparoscopy, because it has proven that it doesn't show up on your ultrasounds very well at all.[34]
>
> When I had the ultrasound, it did not show any endometriosis whatsoever, nothing. It came back and the gynaecologist said, 'Your results are clear. There is no endometriosis on your ultrasound.[35]

Nevertheless, based on evidence from research, the 2022 ESHRE Guidelines for Endometriosis has recommended imaging, such as transvaginal ultrasound scan (TVUSS) and magnetic resonance imaging (MRI), as additional diagnostics tools.[36] While imaging tools might not be able to 'always detect the endometriosis lesions' [37] nor 'individually be sufficient

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[29] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. 34.

[30] Robinson Research Institute, *Endometriosis Adelaide Endometriosis Research Group,* Robinson Research Institute website, 2023, accessed 12 March 2024. Also see Committee Hansard: Adelaide Pelvic Pain Network.

[31] Committee Hansard: Sonographers (Alison Deslandes), 1 May 2024, p. 20.

[32] European Society of Human Reproduction and Embryology (ESHRE), *Information on Endometriosis Patient Leaflet based on the ESHRE Guideline on Endometriosis,* ESHRE, 2022.; Robinson Research Institute, *Endometriosis Adelaide Endometriosis Research Group*; In the evidence provided to the committee, the histological confirmation is seldom mentioned and only laparoscopy is noted as the gold standard (See for example Committee Hansards: Berri Hearing (Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Rochana and Shannon Watkins, 10 July 2024; Submissions: 10, 75.

[33] Committee Hansard: Adelaide Pelvic Pain Network, 10 July 2024.

[34] Committee Hansard: Berri hearing (Amara Turner), 12 June 2024, p. 100.

[35] Committee Hansard: Lucy Lines, 18 September 2024, p. 288.

[36] See for example Committee Hansards: Sonographers, 1 May 2024; Robinson Research Institute, 15 May 2024; Adelaide Pelvic Pain Network, 10 July 2024; Submissions: 4, 10.

[37] ESHRE (2022) *Information on Endometriosis Patient Leaflet based on the ESHRE Guideline on Endometriosis,* ESHRE, *Endometriosis guideline,* accessed 10 April 2024, p. 6.

to replace surgery,'[38] they are useful less or non-invasive diagnostic tools that will cause minimal pain or discomfort to persons with endometriosis.[39]

While the ESHRE Guidelines for endometriosis has acknowledged imaging, such as TVUSS and MRI, as useful in diagnosing endometriosis, there is slow uptake of TVUSS in specialised gynaecological imaging centres to community practice. Avery et al., reported that in the case of TVUSS, sonographers want more specific guidelines for its perfomance, because 'the absence of TVUSS guidelines leaves sonographers trailing in the field…[40] Ms Deslandes mentioned three reasons for this slow uptake of imaging in her evidence to the committee, namely 'it takes a long time for medical research to translate to clinical practice, the national guidelines don't yet mandate that endometriosis be part of routine pelvic ultrasound', and 'we don't yet have the workforce skilled enough for everybody to be able to do it as well.'[41]

Furthermore, the evidence presented to the committee implies that a much more concise set of guidelines would be more helpful, especially for GPs, who are often the first point of contact for individuals with endometriosis related symptoms. In a survey conducted amongst GPs, researchers from the Robinson Research Institute of the University of Adelaide reported that two thirds of the respondents wanted more concise guidelines for GPs:

> … Currently, the RANZCOG guidelines are 70 pages, and the ESHRE guidelines are 192 pages… We need targeted guidelines focusing on GPs that are quickly and easily accessible to aid effective primary care management for patients with endometriosis.[42]

Some evidence provided to the committee also implied that not all clinicians are aware of the ESHRE or even RANZCOG guidelines. Submissions from mothers who have children with endometriosis reflected this issue.[43] Ms Dance, who suffers from endometriosis herself and has two daughters whom she suspects of having endometriosis related symptoms, articulated in her submission that many GPs have overlooked her daughters' conditions. She requested the committee to create 'guidelines to identify early signs of endometriosis for GPs, hospital staff, community nurses and specialists (including the Gender Clinic and WCH) and guidelines and pathways for referrals to specialists when initial attempts do not resolve the symptoms.'[44] The submission from Ms Natalie Mason, who has a daughter who has endometriosis, requested for guidelines on 'what to do with such a young patient.'[45]

The ESHRE Guidelines for Endometriosis, especially the 2022 version, is a significant document for the diagnosis, treatment, and management of endometriosis, with its recommendation of imaging as a useful diagnostic tool for endometriosis. However, there is still a slow uptake of the techniques, lack of awareness among some clinicians of the

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[38] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. C33.
[39] See for example Committee Hansards: SHINE SA, 10 July 2024; Julia Argyrou Endometriosis Centre at Epworth Healthcare (JAECE), 30 October 2024; Submissions: 20, 33.
[40] JC Avery, et al., 'Noninvasive diagnostic imaging for endometriosis part 1: a systematic review of recent developments in ultrasound, combination imaging, and artificial intelligence', p. 184.
[41] Committee Hansard: Sonographers (Alison Deslandes), 1 May 2024, p. 20.
[42] Submission 37, no page numbers.
[43] Submissions: 26, 51.
[44] Submission 26, no page numbers.
[45] Submission 51, p. 2.

Guidelines, and that the length of the guidelines still calls for a more succinct set of guidelines that GPs can easily and quickly comprehend and employ in their practices.

7.4 Endometriosis Management Plan Project and Endometriosis Living Guidelines

Other than the chronic disease management plan, the evidence received by the committee indicates that Commonwealth Government funding has been allocated for the creation of endometriosis living guidelines and endometriosis management plans. In DHAC's presentation to the committee, Ms Schofield reported that as complimentary projects to the 22 endometriosis and pelvic pain clinics across Australia, the Commonwealth Government has also funded the development of an endometriosis living guideline to 'support new and ongoing research into the diagnosis and management of endometriosis, including pain management.'[46]

The Commonwealth Government is also funding the Endometriosis Management Plan project. The project aims to develop and implement an endometriosis management plan to support clinicians, especially GPs, and their patients in navigating and managing endometriosis in terms of services, activities, and health and medical providers. Ms Schofield from DHAC said that the endometriosis management plan is hoped to assist consumers have 'a better sense of where to go when and which clinicians or allied health support are needed at various points in their treatment and management journey.'[47]

Moreover, the submissions from Thrive Family Practice (25-2) indicates that they create an Endo Action Plan for their patients.[48] Thrive Family Practice is one of two Commonwealth Government funded endometriosis and pelvic pain clinics in South Australia. Dr Alecia Macrow, a GP and the Director of Thrive Family Practice, explained that they have developed an Endo Action Plan to equip 'patients with the knowledge and tools they need to proactively manage their endometriosis.'[49] The plan

> focuses on 'preventers,' such as menstrual suppression and techniques to relax the pelvic floor, and 'relievers' like regular simple analgesia for flare ups. This structured approach has empowered many of our patients to take control of their condition and manage their symptoms more effectively.[50]

As part of NAPE's implementation, the Commonwealth Government has yet to settle on the formulation of an endometriosis clinical guideline but is funding the drafting of an endometriosis living guideline and endometriosis management plan. In the absence of guidelines, Thrive Family Practice has taken the initiative to create an endometriosis action plan for their patients, that allows them to be ready with a system and process that will help patients manage their symptoms, understand their triggers and help them address these early.

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[46] Committee Hansard: DHAC (Lisa Schofield), 25 September 2024, p. 306.
[47] Committee Hansard: DHAC (Lisa Schofield), 25 September 2024, p. 310.
[48] Submission 25-2.
[49] Submission 25-2, no page numbers.
[50] Submission 25-2, no page numbers.

8. CURRENT TREATMENT AND SUPPORTS AVAILABLE, THEIR EVIDENCE-BASED EFFECTIVENESS, AND POTENTIAL SIDE EFFECTS

A common description of what individuals with endometriosis go through in their journey to seeking and securing diagnosis, treatment, and management is that the experience is multi-faceted, long, relative to getting a care plan that is suitable to each person's circumstances, and a mix of trial and error.

8.1 Diagnosis of endometriosis

Up until 2008, a definitive diagnosis of endometriosis was only via laparoscopy. Laparoscopy is a "keyhole' operation in which the surgeon uses a low diameter telescopic system, a laparoscope, to examine or operate on an area in a woman's pelvis.'[1] The procedure is done under general anaesthesia. In their presentation, Professor Hull, Head of the Adelaide Endometriosis Research Group at the Robinson Research Institute, University of Adelaide, explained how laparoscopy is done to search for endometriosis.

> When you do a laparoscopy[,] you look over the front of the uterus and sometimes it is there. At the back of the uterus, which is usually where it is, right behind the uterus, that is the most common position, but sometimes it is up on the diaphragm[,]and they would always look over the liver. So then they rotate the scope and look upwards…[2]

Laparoscopy is an invasive diagnostic tool. The evidence submitted to the committee shows that there is a long waitlist to get a laparoscopy that could have been helpful in addressing the diseases early on.[3] Laparoscopy as a treatment and management option will be discussed in the sub-section Treatment and management options.

The long waitlist to get a laparoscopy in the public health system,[4] the high cost of getting the procedure,[5] and the invasive nature of laparoscopy,[6] impacts the treatment and management of endometriosis. Hence, health and medical practitioners have investigated other tools to detect endometriosis as early as possible. Imaging, such as TVUSS and MRI are now backed by research as useful diagnostic tools for endometriosis. Considered a 'quantum leap' in the field, Associate Professor Condous explained that laparoscopy will only be resorted to if 'imaging is negative.'[7] Accordingly, the long wait to get a diagnosis can be reduced.[8]

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[1] ESHRE *Information on Endometriosis Patient Leaflet based on the ESHRE Guideline on Endometriosis,* p. 21.

[2] Committee Hansard: Robinson Research Institute, 15 May 2024, p. 42.

[3] See for example Committee Hansard: Berri hearing (Kaye Schober, Amara Turner), 12 June 2024; Submissions: 24, 25-2, 44.

[4] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Pelvic Pain Foundation of Australia, 5 June 2024; Berri hearing (Kaye Schober), 12 June 2024; Submissions: 10, 24.

[5] See for example Committee Hansards: Sonographers, 1 May 2024; Pelvic Pain Foundation, 5 June 2024; Submissions: 34, 38.

[6] See for example Committee Hansards: Berri hearing (Amara Turner), 12 June 2024; Associate Professor George Condous, 10 July 2024; Submission: 20.

[7] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 141; also see Committee Hansard: Robinson Research Institute (Dr Jodie Avery), 15 May 2024, p. 41.

[8] See for example Committee Hansard: Dr Monique Kanters, 18 September 2024.

[8] Committee Hansard: Dr Monique Kanters, 18 September 2024, p. 19.

Imaging is also seen as useful in planning for laparoscopy or relevant surgery to treat and manage endometriosis. Ms Deslandes, a specialist sonographer and current PhD student with the Robinson Research Institute at the University of Adelaide explained that imaging before undergoing surgery can inform triage.

> If there is more advanced disease with a lot of adhesions and a lot of distortion of the pelvic anatomy, those patients really need to go onto the advanced surgical teams; whereas people who have isolated stage 1 disease can usually be managed by a general gynaecologist quite adequately.[9]

Understandably, the evidence received by the committee shows support towards imaging as an alternative diagnostic tool for endometriosis.[10]

In order to detect endometriosis via TVUSS, the sonographer performing the procedure must be skilled in this area. In their presentation to the committee, Ms Deslandes and Ms Maple, another specialist sonographers, emphasised that at present, becoming an expert in endometriosis TVUSS involves reading relevant literature, attending conferences and workshops, and working alongside expert sonographers. These activities are often driven by an individual’s interest and are personally funded.

> … it is very much driven by the individuals. It is usually done out of people's goodwill. Every now and again, I will have people come and work with me… and nothing is formalised. And it is all usually funded by the individuals themselves, so a lot of the people who are doing this are people who have reached out to get their own education and paid to go on courses and things like that…[11]

Amidst the confirmation of imaging as a useful tool to detect endometriosis, evidence received by the committee note that specialist imaging, and even scanning centres, are not widely available in South Australia.[12] For this reason, opportunities for sonographers to perform hands-on scanning for endometriosis is limited.[13] Evidence presented to the committee also indicates that expert sonographers are mostly located in Adelaide, and in the private health sector, making access to these specialist sonographers challenging for those in regional and rural areas.[14] More details on these issues are in Section 9.

As outlined above, diagnosis of endometriosis can now be done via laparoscopy or imaging, particularly TVUSS and MRI. Laparoscopy is still recommended for diagnosis, but only if no endometriosis is detected after an TVUSS or MRI. Imaging is not only useful in terms of facilitating early detection of endometriosis and reducing the long wait time to get clinical confirmation of the disease, but also in coordinating appropriate and timely triage for individuals suffering with the disease. Sonographers must have a certain level of expertise or

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[9] Committee Hansard: Sonographers (Alison Deslandes), 1 May 2024, p. 19.

[10] See for example Committee Hansards: Sonographers, 1 May 2024; Robinson Research Institute, 15 May 2024; Rochana Watkins and Shannon Watkins, 10 July 2024; Submissions: 40, 51.

[11] Committee Hansard: Sonographers (Alison Deslandes), 1 May 2024, p. 29.

[12] See for example Committee Hansards: Sonographers, 1 May 2024; Robinson Research Institute, 15 May 2024; Submission: 33.

[13] Committee Hansard: Sonographers, 1 May 2024.

[14] See for example Committee Hansards: Sonographers, 1 May 2024; Associate Professor George Condous, 10 July 2024; Submissions: 33, 37, 42.

skill to accurately perform the procedures, especially TVUSS. TVUSS upskilling among sonographers, nevertheless, is driven by self-interests and is self-funded, that could be a contributing factor to the current lack of specialist imaging experts in the state. Consequently, access to specialist imaging becomes difficult for individuals who prefer less or non-invasive diagnostic procedures, especially for those who are living outside the metropolitan areas.

8.2 Treatment and management options

The evidence submitted to the committee identified that the treatment and management of endometriosis involves a mixture of analgesics, hormone therapies, non-drug and non-hormonal treatment, and surgery.

Analgesics and hormone therapies

The evidence presented to the committee shows that pain relief medicines and hormone therapies are commonly prescribed for treating and managing endometriosis. These options are generally raised by clinicians during the initial consultations.[15] The evidence provided to the committee reveals that paracetamol and non-steroidal anti-inflammatory medicines, like ibuprofen, are often prescribed by clinicians or bought without a prescription by individuals with endometriosis, to relieve pain.[16] As these drugs only provide temporary relief, the evidence received articulated that individuals who suffer from endometriosis would combine their intake of pain relief medicines or shift from one brand to another.[17]

> The way that I would stop the pain from those periods was a cocktail of Panadol, Nurofen and Donnatab. Donnatab is an antispasmodic. I would take two each—two Panadol, two Nurofen, two Donnatab—and that would wipe me out.[18]

Hormone therapies, like analgesics, reduce the pain associated with endometriosis, but also minimises its severity through 'suppressing the growth of endometrial cells and stopping any bleeding.'[19] The evidence submitted to the committee indicates that combined oral contraceptive pill (COCP),[20] progestogens,[21] such as the Mirena, and gonadotrophin-releasing hormone analogues (GnRHa), [22] such as Zoladex, are the hormone therapies often prescribed to or used by people with endometriosis. The GnRH according to Professor Abbott has recently been used in Australia for the treatment and management of endometriosis,[23] and was generally mentioned in the evidence presented to the committee from the regional hearing in Berri.

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[15] See for example Committee Hansards: Berri hearing (Jesse Lang, Amara Turner), 12 June 2024; Amy Aikman, 10 July 2024; Submissions: 3, 6, 7, 9.

[16] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Christie Nancarrow, 19 June 2024; Ms Rochana Watkins and Mr Shannon Watkins, 10 July 2024; Amy Aikman, 10 July 2024; Gayelene Allen, 18 September 2024; Submissions: 2, 9, 10, 19, 21.

[17] See for example Committee Hansards: Dr Jane Chalmers; 10 April 2024; Gayelene Allen, 18 September 2024; Submissions: 31, 32.

[18] Committee Hansard: Gayelene Allen, 18 September 2024, p. 287.

[19] Jean Hailes for Women's Health, Endometriosis: Symptoms & causes.

[20] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Adelaide Pelvic Pain Network, 10 July 2024; Submission: 24.

[21] See for example Committee Hansard: Lucy Savage, 18 September 2024: Submissions: 14, 23.

[22] See for example Committee Hansards: Berri hearing (Amara Turner), 12 June 2024; Deanna Flynn Wallis, 19 June 2024; Rochana Watkins and Shannon Watkins, 10 July 2024; Submissions: 18, 22, 62, 68.

[23] Committee Hansard: Dr Alex Liew; 11 September 2024.

Dienogest (Visanne) and Ryeqo (a tablet containing three different active ingredients relugolix, estradiol and norethisterone) are the two new hormone therapies mentioned in the evidence presented to the committee.[24] Also noted in the evidence provided are the side effects of these hormone therapies causing users to often change their hormone medicines.[25] For example, the COCP have some negative impact on the mental health of some users.[26]

> During my time on the pill and approximately around the ages of 18 to 23, I experienced periods of anxiety, depression, and panic attacks which impacted my quality of life. I don't look back at this time of my life favourably.[27]

With GnRHA such as Zoladex, the evidence submitted to the committee notes of induced menopause as a major side effect.[28] In her presentation to the committee, Ms Turner said that while Zoladex was a good pain reliever, it 'chemically put me into full-blown menopause instantly. It's a bad enough experience going through that naturally, rather than when you are induced into it so very suddenly. I ended up in hospital.'[29] Furthermore, the search for an effective and suitable treatment and management option is the other reason that individuals with endometriosis shift from one hormone therapy to another.[30]

As has been noted, pain relievers and different hormone therapies are used to treat and manage endometriosis. Often, taking one type of analgesic is deemed inadequate to relieve pain so people with endometriosis try different painkillers. As for hormone therapies, the differences in people's tolerance impacts the effectiveness of each hormone therapy. For this reason, hormone medicines do not necessarily have the same effect for each person with endometriosis. Accordingly, the change from one hormonal treatment to another is inevitable, which has implications towards access and availability of alternative treatment and management options, not to mention cost. More of these matters are discussed in Section 9.

Surgery

The evidence provided to the committee shows that laparoscopy,[31] hysterectomy,[32] oophorectomy,[33] and ablation[34] are the surgeries performed to treat and manage

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[24] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Deanna Flynn Wallis, 19 June 2024; Submissions: 21, 24, 67.

[25] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Georgia Gosse, 10 July 2024; Dr Alex Liew, 11 September 2024; Gayelene Allen, 18 September 2024; Submissions: 26, 36, 40.

[26] See for example Committee Hansards: Berri hearing (Jesse Lang), 12 June 2024; Georgia Gosse 10 July 2024; Gayelene Allen, 18 September 2024; Submissions: 9, 68.

[27] Committee Hansard: Berri hearing (Jesse Lang), 12 June 2024 p. 103.

[28] See for example Committee Hansard: Berri hearing (Dr Nasser Shehata, Amara Turner), 12 June 2024; Deanna Flynn Wallis, 19 June 2024.

[29] Committee Hansard: Berri hearing (Amara Turner), 12 June 2024, p. 96.

[30] See for example Committee Hansards: Lucy Savage, 18 September 2024; Stacey Seedon, 18 September 2024; Submissions: 6, 26, 29, 47.

[31] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Christie Nancarrow, 19 June 2024; Associate Professor George Condous, 10 July 2024; Rochana Watkins and Shannon Watkins, 10 July 2024; Gayelene Allen, 18 September 2024; Submissions: 4, 9, 14, 20.

[32] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Berri hearings (Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Deanna Flynn Wallis, 19 June 2024; Associate Professor George Condous, 10 July 2024; Submissions: 2, 14, 18, 19.

[33] See for example Committee Hansard: Berri hearing (Dr Nasser Shehata, Amara Turner), 12 June 2024; Thrive Family Practice, 28 August 2024; Dr Collin Weatherill, 21 October 2024; Submissions: 3, 14, 62.

[34] See for example Committee Hansard: Berri hearing (Amara Turner), 12 June 2024; Stacey Seedon, 18 September 2024; Submission: 6.

endometriosis. As previously noted, laparoscopy is both a diagnostic and treatment tool. Laparoscopy is the most common surgical procedure to remove endometriosis, hoping to reduce development of adhesions, for better health outcomes for the patient.[35] Henceforth, it is essential to have a highly skilled surgeon for the procedure.

Hysterectomy or the removal of the uterus can be prescribed and done to treat and manage endometriosis. The evidence provided to the committee emphasises that a hysterectomy does not cure endometriosis, as some clinicians may tell their patients.[36] However, the evidence received by the committee, especially from those people who have endometriosis or have family members with the condition and had a hysterectomy, presents a mix of both negative[37] and positive outcomes.[38] As a hysterectomy is performed to attend to the severe pain caused by endometriosis, the evidence submitted to the committee stressed that it should only be resorted to if the woman decides that she no longer wants to get pregnant.[39]

Other than the removal of the uterus, the taking out of one or both of the ovaries, or oophorectomy, is also indicated in the evidence to relieve pain from endometriosis.[40] As the ovaries produce hormones that control the menstrual cycle, removing them will stop the cycle, that might also cease the growth of endometriosis, thus alleviating pain from the disease. The evidence presented to the committee implies that oophorectomy might only be resorted to for severe cases.[41]

Finally, the evidence provided to the committee mentioned ablation or endometrial ablation as a surgical procedure to attend to endometriosis related symptoms.[42] In this procedure, the endometrium is removed to reduce pain and menstrual bleeding.[43] Like a hysterectomy, ablation should only be performed if women or those AFAB no longer want or plan to have children.[44]

The evidence received by the committee implies that people with endometriosis often have more than one laparoscopy to treat their conditions. Persons with endometriosis undergo two or more laparoscopies because of the recurrence of endometrial tissues[45] or the lack of expertise of the gynaecologists during the surgery.[46] In some cases, individuals with endometriosis report the disease getting worse.[47]

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[35] See for example Committee Hansard: Sonographers, 1 May 2024; Submissions: 47, 50.

[36] See for example Committee Hansard: Dr Jane Chalmers, 10 April 2024; Submissions: 70, 72.

[37] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Adelaide Pelvic Pain Network, 10 July 2024; Lucy Lines, 18 September 2024; Submissions: 18.

[38] See for example Committee Hansard: Adelaide Pelvic Pain Network, 10 July 2024; Submissions: 2, 83.

[39] See for example Committee Hansard: Associate Professor George Condous, 10 July 2024; Berri hearing (Amara Turner), 12 June 2024; Christie Nancarrow, 19 June 2024; Submissions: 2, 63, 83.

[40] See for example Committee Hansard: Berri hearing (Dr Nasser Shehata, Amara Turner) 12 June 2024; Submission: 3.

[41] See for example Committee Hansard: Berri hearing (Amara Turner), 12 June 2024; Submissions: 68, 81.

[42] See for example Committee Hansard: Berri hearing (Dr Nasser Shehata, Amara Turner), 12 June 2024; Stacey Seedon, 18 September 2024; Submissions: 31, 50, 58.

[43] RANZCOG, *Endometrial ablation,* https://ranzcog.edu.au/wp-content/uploads/Endometrial-Ablation.pdf, accessed 17 January 2025. Also see Committee Hansard: Berri hearing (Dr Nasser Shehata, Amara Turner), 12 June 2024.

[44] Submissions: 6, 68.

[45] J Crump, A Suker and L White, "Endometriosis: A review of recent evidence and guidelines'. Also see Committee Hansards: Robinson Research Institute, 15 May 2024; Deanna Flynn Wallis, 19 June 2024; RANZCOG, 10 July 2024; Stacey Seedon, 18 September 2024; Submissions: 6, 7, 9.

[46] See for example Committee Hansard: Adelaide Pelvic Pain Network, 10 July 2024; Submissions: 24, 26, 54.

[47] See for example Committee Hansards: Gayelen Allene, 18 September 2024; Submissions: 9, 26, 27.

In some cases where endometriosis is severe and/or found in other organs such as the bladder or bowel, other specialists, such as a urologist or colorectal surgeon, may need to be present during the surgery.[48] The procedure to treat severe endometriosis is called laparotomy – an open surgery. The evidence given to the committee noted that when surgeons discover the presence of endometriosis in other organs or severe endometriosis during the first laparoscopy, they might call for follow-up surgery.[49] While the evidence presented to the committee articulates that laparoscopy generally provides relief to individuals with endometriosis, repetition of the procedure was not necessarily seen to have better outcomes to the overall quality of life for individuals with endometriosis.[50]

Other than having more laparoscopies, the evidence given to the committee further revealed that some individuals with endometriosis have more than one type of surgery.[51] For instance, Ms Flynn Wallis has a history of using multiple hormonal therapies, but also 'multiple laparoscopies … been put into temporary menopause four times,' and had a hysterectomy in April last year (2023).'[52] Undergoing repeated surgery to treat and manage endometriosis is not advisable due to its detrimental effect on a person's quality of life,[53] including fertility.[54] In addition, having multiple surgeries also mean additional costs.[55] Clinicians should explain to individuals going for surgery that the procedure 'is not a cure for endometriosis.'[56]

A combination of surgery and other treatment is deemed to improve outcomes.[57] Ms Schober from Berri said that her surgeon did a 'holistic approach' towards the treatment and management of her endometriosis. Ms Schober shared that prior to having laparoscopy, she was advised to take in natural supplements such as fish oil to reduce inflammation. She also took other supplements to help with fertility and inflammation such as zinc and magnesium.[58] The ESHRE and RANZCOG Guidelines also proposed that hormonal therapies should be given post-laparoscopy.[59] In the evidence provided to the committee, this method seems to not always work for everyone.[60]

In general, laparoscopy, hysterectomy, oophorectomy, and endometrial ablation are the surgeries performed to treat and manage endometriosis. With the recurrence of endometriosis, individuals with the condition go for more than one surgical operation to manage endometriosis associated symptoms. Repeated surgery does not necessarily result in a better quality of life for individuals with endometriosis, thus, clinicians should explain to

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[48] See for example Submission 22.

[49] See for example Committee Hansard: Robinson Research Institute (Professor Louise Hull), 10 July 2024; Gayelene Allen, 18 September 2024; Submissions: 3, 4.

[50] See for example Committee Hansards: Professor Jason Abbott, 11 September 2024; Submissions: 14, 27.

[51] See for example Committee Hansards: Berri hearing (Jesse Lang), 12 June 2024; Ms Deanna Flynn Wallis, 19 June 2024; Submissions: 21, 25-2.

[52] Committee Hansard: Deanna Flynn Wallis, 19 June 2024, p. 126.

[53] See for example Committee Hansard: Deanna Flynn Wallis, 19 June 2024; Professor Jason Abbott, 11 September 2024; Submission: 68

[54] J Crump, A Suker and L White, "Endometriosis: A review of recent evidence and guidelines'; Also see Submissions: 68.

[55] See for example Submissions: 31, 34, 36.

[56] J Crump, A Suker and L White, "Endometriosis: A review of recent evidence and guidelines', p. 14

[57] See for example Committee Hansards: Berri hearing (Kaye Schober), 12 June 2024; RANZCOG, 10 July 2024.

[58] Committee Hansard: Berri hearing (Kaye Schober), 12 June 2024, p. 87.

[59] J Crump, A Suker and L White, 'Endometriosis: A review of recent evidence and guidelines'.

[60] See for example Submissions: 18, 47, 77.

their patients that surgery may not be a cure for endometriosis. The ESHRE and RANZCOG Guidelines may recommend that clinicians prescribe hormonal treatment after laparoscopy for endometriosis, but the evidence given to the committee states that this method does not always have beneficial outcomes.

Conservative therapeutic methods and natural therapies

Non-drug and surgery options are also available to treat and manage endometriosis-related symptoms, especially pain.[61] Conservative treatments are generally non-invasive and include allied health services such as pelvic floor physiotherapy, psychological and psychotherapeutic procedures, diet and nutrition, heat treatment, and acupuncture. The evidence presented to the committee indicates that people with endometriosis access and avail one or more non-medical therapies to help address endometriosis related symptoms,[62] and to some degree, have a sense of control over their conditions.

Access to these conservative therapeutic methods or allied health services is built into the Medicare chronic disease management plan for patients and their doctors to consider in their plan for care.[63] Five allied health service visits are allocated as part of the chronic disease management plan. The evidence submitted to the committee, stressed that this number of visits is inadequate, considering that endometriosis is a chronic disease, and that this number of allocations is spread over all types of allied health services.[64]

> … the issue we find with endometriosis is with the team care arrangement you might only end up having two or three sessions allocated to physio. If someone needs to see a dietician, then it's a total of five across all disciplines within 12 months. So it's not five physio and five dietetics and whichever multidiscipline team they need…[65]
>
> With the nature of endometriosis and it being chronic, it is well more than five sessions. It is about building that toolkit. Obviously not everyone is willing or can afford to continue as a full fee paying client, so we will attempt to give you as much support and these resources as we can in two sessions, for example, but ideally, it's something that you would like to be checking in somewhat regularly, which again is limited by those Medicare sessions.[66]

In their presentation to the committee, Ms Colton, from Medicare Benefits and Digital Health Division of DHAC said that this concern is considered in the current review of the MBS by an independent clinical committee.[67] Additionally, while there is acknowledgement of the benefits of physiotherapy, psychological and psychotherapeutic procedures to alleviating the

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[61] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Dr Alex Liew, 11 September 2024; Submissions: 40.

[62] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; RANZCOG, 10 July 2024; Submissions: 60.

[63] See for example Committee Hansard: Professor Jason Abbott, 11 September 2024; Submission: 70.

[64] See for example Committee Hansard: Berri hearing (Elizabeth Eske), 12 June 2024; Sarah Coshan, 18 September 2024.

[65] Committee Hansard: Eloise Zanoni, 18 September 2024, pp. 275-276.

[66] Committee Hansard: Emma Dempster, 18 September 2024, p. 296.

[67] Committee Hansard: DHAC (Imogen Colton), 25 September 2024, pp. 309-310.

symptoms and side effects of people with endometriosis, more empirical studies seemed to be required to ascertain the effectiveness of these conservative therapeutic models.[68]

Apart from allied health services, the evidence provided to the committee notes that individuals suffering from endometriosis also utilise some forms of natural therapy. Examples of natural therapies include 'supplements (vitamins, minerals and fish oils), herbal medicine (tea, tablets and liquids) and nutrition.'[69] Like the conservative therapeutic methods, more large studies are needed to support the usefulness of these methods in managing endometriosis symptoms.[70]

In general, individuals with endometriosis resort to non-pharmacological and non-surgical means to manage endometriosis, such as allied health services and natural therapies. There is strong evidence of the impact of endometriosis to the physical and psychological make-up of those with the condition that accessing conservative and natural therapeutic method is understandable – it somehow brings a sense of control over one's condition. Nonetheless, Medicare funding for all types of allied health services is limited to five visits in a 12-month period. Medicare is currently reviewing this matter. Furthermore, more research is needed to strongly evaluate the effectiveness of conservative and natural therapeutic methods.

Opioids and Pelvic Floor Botox

Though not everyone with endometriosis experiences persistent pelvic pain, many of those who have endometriosis suffer from chronic pelvic pain. Pain killers are often prescribed to address the pain, but some of those who have severe conditions use opiates.[71] This situation is reported in some of the evidence provided to the committee and is something that is not only considered harmful,[72] but also aggravates endometriosis.[73]

Nevertheless, for some of those who are in chronic pain and could not afford having a multidisciplinary team to treat and manage their conditions, the presentation from Dr Clare Keogh of SHINE SA implied that individuals suffering from persistent pelvic pain due to endometriosis are prescribed opiates.

> Sometimes it means that in the end they (patients) are not able to go to a pelvic floor physio, see a dietician and those sorts of things, but they are still in a lot of pain, so you are in the difficult situation of deciding about pain medication and whether you should be putting them on certain medications. I really, really try to avoid opiates because there is so much harm associated with them, and they quite frankly don't work for very long and they are not good medicine, but they are cheap and accessible, basically.[74]

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[68] J Crump, et al., 'Endometriosis: A review of recent evidence and guidelines'.
[69] Jean Hailes for Women's Health, Endometriosis: Symptoms & causes. Also see Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Rochana Watkins, 10 July 2024; Amy Aikman, 10 July 2024; Georgia Gosse, 10 July 2024).
[70] J Crump, et al., 'Endometriosis: A review of recent evidence and guidelines'.
[71] R Wilkinson, M Wynn-Williams, A Jung, J Berryman and E Wilson. 'Impact of a Persistent Pelvic Pain Clinic: Emergency attendances following multidisciplinary management of persistent pelvic pain', *The Australian & New Zealand journal of obstetrics & gynaecology,* 2021, 61(4): 612-615, doi:10.1111/ajo.13358. doi:10.1111/ajo.13358.
[72] See for example Committee Hansards: PPFA, 5 June 2024; SHINE SA, 10 July 2024; Submission: 11.
[73] Committee Hansard: RANZCOG, 10 July 2024.
[74] Committee Hansard: SHINE SA (Dr Clare Keogh), 10 July 2024, p. 147.

The above condition is problematic as it indicates that individuals with endometriosis might be willing to engage in the treatment and management of their disease, yet will eventually give up due to the difficulty in accessing appropriate care plans. In RANZCOG's presentation to the committee, Dr Magdalena Halt, a gynaecologist and RANZCOG Councillor (SA), admitted weaning patients who have taken multiple opiates as very challenging.

> … I personally sometimes feel out of my depth with chronic pain patients who are on multiple opiates and multiple neuropathic medications. I don't feel confident to wean them off it in a way that is appropriate, and I feel [that with] those patients particularly I have no way of progressing, because they can't get to see a chronic pain person. They are very much at the forefront of my mind because nothing will improve for them when they are on that level of medication. We can't progress… It is hard…[75]

The evidence received by the committee also reported pelvic floor botulinum toxin or botulinum neurotoxin (Botox) as a means to manage persistent pelvic pain.[76] Similar to opiates, Botox is down the list of options to managing chronic pelvic pain due to endometriosis, mainly for two reasons – limited accessibility[77] and cost.[78] At the moment, the Botox injection is not offered in the public health system as it is considered a cosmetic treatment,[79] with costs ranging from $275[80] to $750 after 'top-tier private' rebates.[81] In addition, like other treatment and management options, Botox's efficacy towards pelvic pain relief is variable. In her submission to the committee, Ms Elston described pelvic floor Botox as 'revolutionary' in terms of easing her pain and with no side effects.[82] Her submission implies a 6-months effectiveness of the Botox injection.

Nonetheless, in Adelaide Pelvic Pain Network's presentation to the committee, Dr Reynolds, one of the GP members of this network, articulated the difficulty in figuring out 'who it (Botox) will work for', seeing some patients with good outcomes from the injection.[83] Similar to the use of opioids, the presentation from Dr Macrow indicated that having a multidisciplinary team to look after the treatment and management of endometriosis among people who have the condition, reduces the chance of them requiring pelvic floor Botox.[84]

In summary, in the search for ways to reduce pelvic pain from endometriosis, some individuals with the condition also use opiates and have pelvic floor Botox injections. While opioids are harmful with continuous usage, it relieves severe pelvic pain and is cheaper than other alternatives. Those who can financially afford Botox get it as it can work for about 6 months in reducing persistent pelvic pain. However, pelvic floor Botox is expensive and not offered in

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[75] Committee Hansard: RANZCOG (Dr Magdalena Halt), 10 July 2024, p. 219.

[76] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Thrive Family Practice, 28 August 2024; Dr Alex Liew, 11 September 2024; SA Unions, 13 November 2024; Submissions: 24, 36.

[77] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; Thrive Family Practice, 28 August 2024.

[78] See for example Committee Hansards: Thrive Family Practice, 28 August 2024; SA Unions, 13 November 2024; SA Unions, 13 November 2024; Submissions: 36, 38.

[79] See for example Submission 36.

[80] Committee Hansard: Vagenius Training, 27 August 2024.

[81] Submission 24, p. 5.

[82] Submission 24, p. 5.

[83] Committee Hansard: Adelaide Pelvic Pain Network (Dr Carmel Reynolds), 10 July 2024, p. 145

[84] Committee Hansard: Thrive Family Practice, 28 August 2024.

the public health care system limiting the number of individuals who can access the treatment. Yet the evidence submitted to the committee notes that a multidisciplinary care model for the treatment and management of endometriosis lessens the chances of individuals with the condition needing opioids and pelvic floor Botox.

In conclusion, the diagnosis, treatment and management of endometriosis involves a mixture of medical and non-medical procedures. In terms of diagnosis, the recent clinical guidelines for endometriosis have acknowledged the capacity of imaging tools, such as TVUSS and MRI, to detect the disease. This development is set to reduce the waiting time for diagnosis and serve as options to those who prefer less or non-invasive diagnostic tools. The results from the imaging can also guide laparoscopic surgery. As for the treatment and management of endometriosis, analgesics, hormonal and non-hormonal therapies, and surgeries are prescribed and done to alleviate the conditions of people with endometriosis.

Based on the evidence given to the committee, everyone's experience of treatment and management differs according to their situation – level of tolerability of the treatment and management option, preferences, priorities, and financial resources. While multiple surgeries are not seen to produce better health outcomes, the evidence presented to the committee reveals that individuals with endometriosis resorted to or underwent more than one surgery. It can be said that going through multiple surgeries along with multi-modal methods of treatment and management is aimed to not only address endometriosis associated symptoms, but also for persons with the condition to gain some sense of control over their lives.

8.3 Models of care and support

The different alternatives and pathways to diagnosing, treating and managing endometriosis and the multiple visits that individuals have to their doctors are not only causing stress to individuals with the condition, but also costing them a large amount of money. The situation necessitates a discussion regarding mechanisms or strategies to holistically address the multi-faceted impact of endometriosis. Below are current and proposed structures to facilitate early diagnosis, treatment, and management of endometriosis.

The multidisciplinary care approach

Both the evidence presented to the committee and relevant literature underscore the importance of a multidisciplinary care approach to the treatment and management of endometriosis. The different and multiple treatment and management methods that have varying degrees of efficacy, are deemed to work better if set within the multidisciplinary model, as it involves various treatment providers working together in an interdisciplinary and multidisciplinary way to facilitate effective and efficient treatment and management of endometriosis.[85]

The evidence provided to the committee also strongly recommends the multidisciplinary care approach as the strategy takes into account the biopsychosocial aspects of endometriosis.[86]

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[85] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis

[86] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; Thrive Family Practice, 28 August 2024; Eloise Zanoni, 18 September 2024.

Seeing endometriosis through the biopsychosocial (biological, psychological and social) lens means that the treatment and management options to alleviate a person's condition does not only focus on medical issues but other aspects of the person's life, taking into consideration the whole of the patient's life[87]. This will result to a tailored approach for each patient that can include 'a combination of pharmacotherapy, psychological therapy, physiotherapy, dietary and exercise prescription and subspecialist opinion and intervention.'[88]

The Medicare chronic disease management plan exemplifies the multidisciplinary care approach. The chronic disease management plan is structured to facilitate the coordination of multidisciplinary care, including access to allied health services. In their presentation to the committee, Ms Colton from DHAC elaborated that the chronic disease management plan can be 'general practitioner (GP)-led multidisciplinary care for patients with a chronic condition,' including endometriosis.[89]

The 22 Commonwealth Government funded specialist Endometriosis and Pelvic Pain GP clinics across Australia are also designed to deliver the multidisciplinary approach to care.[90] The separate presentations made to the committee by the two clinics in South Australia - Thrive Family Practice and Yorke Peninsula Pelvic Pain Clinic (Kadina Medical Associates) – presented four common themes in their practices relevant to the multidisciplinary model. First, the patients coming into their clinics are exhausted from utilising multiple treatment and management options with perceived less effective or ineffective outcomes and consulting several medical practitioners, whose treatment and management plans vary. This situation illustrates the 'fragmentation of care' or 'silos' that Dr Macrow, GP and Director of Thrive Family Practice, highlighted in her presentation, as it negates looking at endometriosis via the biopsychosocial (biological, psychological, and social) lens. [91]

Second, initially the multidisciplinary team in the clinics do not involve specialists. The latter comes in after the initial members have conducted their assessment and have done some initial management, particularly in dealing with pelvic pain. In both facilities, the initial members of the multidisciplinary team are GPs, nurses, and allied health professionals such as pelvic physiotherapist and dieticians.

Third, the health and medical practitioners in the team are upskilled or have expertise in dealing with pelvic pain and endometriosis. As noted earlier, the lack of appropriate level of expertise in the field not only causes delays in diagnosis, treatment, and management of endometriosis, but also leads to a disconnected treatment and management strategy that largely impacts the patient. Dr Kearney explained that,

> Workforce is a big issue for us, as it would be anywhere else. When we look at the numbers, it seems very low… but we tried to work on a service that's going to be able to be an ongoing service in our area and so we employed local pelvic

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[87] See for example Committee Hansards: SHINE SA,10 July 2024; Adelaide Pelvic Pain Network, 10 July 2024; Eloise Zanoni, 18 September 2024.
[88] Committee Hansard: Adelaide Pelvic Pain Network (Dr Carmel Reynolds), 10 July 2024, p. 140.
[89] Committee Hansard: DHAC (Imogen Colton), 25 September 2024, p. 309.
[90] See Committee Hansards: Thrive Family Practice, 28 August 2024; Yorke Peninsula Pelvic Pain Clinic (YPPPC), 13 November 2024.
[91] Committee Hansard: Thrive Family Practice (Dr Alecia Macrow), 28 August 2024, p. 224.

> physiotherapists, and we have employed local GPs who have a special interest in women's health and then upskilled them in these areas.[92]

Hence, and lastly, employing the multidisciplinary care approach involving GP-led conferencing and coordination of both health and medical professionals, alleviates the conditions of these individuals with endometriosis. The overall result from an evaluation study of the Persistent Pelvic Pain Clinic (PPPC) in Queensland, that employs a multidisciplinary approach to managing persistent pelvic pain including those caused by endometriosis, revealed that 'the multidisciplinary PPPC decreased acute pain presentations and short stay admissions to the emergency department'[93] and reduces opiate use among those who were on the medication. In addition, the study showed that there were fewer women who underwent surgery 12 months after receiving multidisciplinary care from the Persistent Pelvic Pain Clinic. In her presentation to the committee, Dr Kearney, a rural generalist and GP obstetrician of the Yorke Peninsula Pelvic Pain Clinic, said that based on a patient reported outcome measures they have set, 'greater than 50 per cent of them feel that they have improved management and self-management of their pain flares and pelvic pain.'[94]

While the benefits of a multidisciplinary care approach are highlighted in the evidence presented to the committee,[95] there are questions regarding the approach's broader implementation considering workforce, service provider remuneration, and time. Table 1 presents evidence of how these factors affect the implementation of the multidisciplinary model of care in consideration of location – metropolitan versus regional.

Table 1. Factors affecting the delivery of the multidisciplinary care approach.

Metropolitan	**Regional**
Workforce	
… we are probably talking about a million women at least across Australia for pelvic pain and all these students. The concept that they are all going to go to an expert multidisciplinary clinic is to my thinking unlikely—very unlikely. Even if there was the funding for a massive additional wing on the Women's and Children's or something like that, where everyone is going to have every appointment, they ever needed, etc., there is nowhere near the workforce.[96]	When you live in a rural area, getting access to multidisciplinary care is really difficult, because there is a lack of specialists that are in our regions, especially those who specialise in endo, and there is also that big pressure on rural generalists to provide that same specialist care while servicing our ever-growing waitlist of other conditions as well.[97]

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[92] Committee Hansard: YPPPC (Dr Anna Kearney), 13 November 2024, p. 367.
[93] R Wilkinson, et al., 'Impact of a Persistent Pelvic Pain Clinic: Emergency attendances following multidisciplinary management of persistent pelvic pain', p. 615.
[94] Committee Hansard: YPPPC (Dr Anna Kearney),13 November 2024, p. 366.
[95] See for example Committee Hansards: SHINE SA, 10 July 2024; JAECE, 30 October 2024.
[96] Committee Hansard: PPFA (Associate Professor Susan Evans), 5 June 2024. p. 64.
[97] Committee Hansard: Berri Hearing (Jenny Han), 12 June 2024, p. 89.

Metropolitan	Regional
Remuneration	
… we did not get recognition for multidisciplinary attendance. Last month, I [thought] I spent about eight or 10 hours pro bono time sitting on multidisciplinary committees, and I was often the only person on those committee who was unpaid.[98]	… as generalists, we also carry that burden to conduct that highly specialised test that we need for endo and we are expected to conduct these scans just as well as the specialists do in metro areas, but without support… One suggestion I have to perhaps tackle this problem is probably increasing support and incentives for rural practitioners to practise in these areas, especially in gynae. [99]
Time	
Because gynaecologists and surgeons are not provided with a Medicare rebate for attending a multidisciplinary meeting, so we do this pro bono. Not everyone would be prepared to spend that time; they may have young kids and other priorities, so they don't want to spend from six to eight [pm]—which is what I was doing yesterday—talking about cases and patients.[100]	In my clinical experience working here, we don't do interdisciplinary care very well, so that's just talking to each other, let alone multidisciplinary care, which is working together. Neither of that is done well. That's something that I really strive to do. The [number] of letters that I send off that go unanswered—it just piles up. I don't often hear back from many people. I don't blame them; I think they probably just don't have time...[101]

While the evidence shown above indicates similarities in how certain factors impact the effective and efficient implementation of the multidisciplinary care approach at the metropolitan and regional levels, being in regional, remote, and rural areas further complicates the delivery of the multidisciplinary model from the perspective of health and medical providers and individuals suffering from endometriosis.[102] To cite, in Adelaide, there is the Adelaide Pelvic Pain Network that consists of independent 'practitioners with extensive experience in managing pelvic pain' working across Adelaide, that also conduct voluntary, multidisciplinary assessments through monthly meetings, where they discuss 'complex cases and share knowledge.'[103] Evidence received by the committee from the regional hearings held in Berri and Mount Gambier made no mention of a similar network in these regions. The comment on this matter from Dr Weatherill, the Head of Unit, Obstetrics and Gynaecology, Mount Gambier and Districts Health Service, provides an explanation why the multidisciplinary approach might not work in regional areas.

> … There are lots of things that happen in cities that will never happen in rural areas, for reasons of numerical mass. How often would you put such a group [multi-

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[98] Committee Hansard: RANZCOG (Dr Magdalena Halt), 10 July 2024, p. 218.

[99] Committee Hansard: Berri Hearing (Jenny Han), 12 June 2024, p. 90.

[100] Committee Hansard: RANZCOG (Dr Magdalena Halt), 10 July 2024, p. 218.

[101] Committee Hansard: Sarah Coshan, 18 September 2024, p. 253.

[102] See for example Committee Hansard: Dr Jane Chalmers, 10 April 2024; Adelaide Pelvic Pain Network, 10 July 2024; Associate Professor George Condous, 10 July 2024; Professor Jason Abbott, 11 September 2024; Submissions: 42, 50.

[103] Committee Hansard: Adelaide Pelvic Pain Network (Dr Carmel Reynolds), 10 July 2024, p. 140.

> disciplinary] together and what would they do when they are not involved in the multidisciplinary meeting? I don't think we can always have in the country what we have in the city.[104]

Given the circumstances mentioned above, the suggestion from the Julia Argyrou Endometriosis Centre Epworth (JAECE) regarding the need to 'assess what the best model of care for multidisciplinary care of endo is' is worth noting.[105] In her presentation to the committee, Dr Tyson, Centre Director of JAECE, advised that doing a study on how the multidisciplinary approach can facilitate efficient use of resources available in a medical facility provides better input to the efficient and appropriate use of resources and services.[106]

In the case of the two endometriosis and pelvic pain clinics in South Australia, in particular, and perhaps all 22 clinics across the country, the presentations to the committee from Associate Professor Condous and that of the Yorke Peninsula Pelvic Pain Clinic suggest some challenge in this area. Both presentations articulated a concern relative to the types of success indicators or standards to use across all clinics to gauge their effectiveness. Associate Professor Condous considered it a 'missed opportunity' that clinics do not have 'central protocols or central guidelines that they tap into,' which means that each clinic crafts 'their own protocols and their own guidelines.'[107] Dr Kearney, from the Yorke Peninsula Pelvic Pain Clinic, pointed out that 'the government reporting requirements continue to change' and 'wanted all of these reporting requirements but couldn't tell us what outcome measures they wanted, how often they wanted them.'[108]

As has been noted, the multidisciplinary care model is considered the ideal strategy towards dealing with individuals who have endometriosis, as it employs a whole of person approach towards the treatment and management of the disease that involves multiple allied health and medical professionals communicating and collaborating. However, there are drawbacks towards the widespread implementation of the multidisciplinary care approach due to factors such as location, remuneration of service providers, the number of skilled workforce vis-à-vis the workload, that affects the amount of time that health and medical practitioners can allocate to provide adequate and tailor-fitted care plans. Generally, living in regional and rural areas makes it challenging to access a multidisciplinary team. Hence, a structured and systematic assessment of the efficiency and effectiveness of the endometriosis and pelvic pain clinics is important to acquire lessons and identify ways to customise the multidisciplinary approach in consideration of the factors mentioned.

Endometriosis clinics or dedicated pain clinics in hospitals and nurse specialist or coordinators

As noted earlier, the funding for the Commonwealth Government funded endometriosis and pelvic plain clinics was aimed at providing patients with a multidisciplinary care and ease the navigation of services and service providers that are needed to decrease delays in diagnosis, treatment, and management of endometriosis. The two funded endometriosis and pelvic pain clinics in South Australia are situated outside tertiary hospitals.

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[104] Committee Hansard: Dr Colin Weatherill, 21 October 2024, p. 340.
[105] Committee Hansard: Endometriosis Australia, 30 October 2024; p. 356.
[106] Committee Hansard: JAECE, 30 October 2024.
[107] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 145.
[108] Committee Hansard: YPPPC (Dr Anna Kearney), 13 November 2024, p. 368.

Given the many and frequent presentations to the emergency departments of hospitals by individuals with endometriosis, to mostly alleviate their pain, and the complexity of the referral pathways,[109] the evidence presented to the committee proposed for the creation of additional endometriosis or pain clinics within tertiary teaching hospitals.[110] Currently, only four out of 15 public hospitals in South Australia have pain management services. These are: Queen Elizabeth Hospital, Flinders Medical Centre, Modbury Hospital, and the Women and Children's Hospital.

In her presentation to the committee, Ms Turner stated that for someone who resides in a regional area, such as Berri, she had to go to Modbury Hospital to receive multidisciplinary pain management services that was very helpful to reduce pain while she waited for her hysterectomy.[111] Endometriosis or pain clinics in regional hospitals would have made it easier for Ms Turner and others living with endometriosis to avail themselves of the services, that in turn, would have reduced cost. Like the Commonwealth Government funded clinics, the evidence received by the committee suggested that endometriosis or pain-specific clinics should be staffed by a multidisciplinary team[112] and 'accessible 24/7'.[113]

In establishing endometriosis or more pain clinics in public hospitals, it is necessary to consider the key challenges indicated earlier regarding creating a multidisciplinary team, namely workforce, remuneration, location, and time. One way to address these obstacles is to include nurses in the multidisciplinary approach. Based on the practice of the two Commonwealth Government funded endometriosis and pelvic pain clinics in South Australia and other evidence presented to the committee, nurses have significant roles to play in the multidisciplinary team.[114] Key roles of nurses in a multidisciplinary team include being the 'touch-point for patients' in navigating treatment pathways to decrease delays in getting care,'[115] providing education to patients',[116] and assisting GPs in intra-uterine device insertions.[117]

The evidence given to the committee also notes that nurses 'may assist in keeping patients away from opioid prescriptions through better support to find alternative strategies to manage pain flares.'[118] Nurses can also provide support to individuals suffering from endometriosis pre- and post-surgery.[119] One presenter from Mount Gambier, Ms Savage, was inspired to consider a nursing career given the care she received from a nurse while under intensive care due to side effects of opioids administered to her after a laparoscopy.[120]

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[109] See for example Committee Hansards: Adelaide Pelvic Pain Network (10 July 2024): JAECE, 30 October 2024; Endometriosis Australia, 30 October 2024.

[110] See for example Committee Hansards: Berri Hearing (Amara Turner), Christie Nancarrow, 19 June 2024; Associate Professor George Condous, 10 July 2024; Endometriosis Australia, 30 October 2024; 32; Submission: 54.

[111] Committee Hansard: Berri Hearing, 12 June 2024.

[112] Committee Hansard: Endometriosis Australia, 30 October 2024.

[113] Committee Hansard: Rochana Watkins, 10 July 2024, p. 140.

[114] See for example Submissions: 34, 37.

[115] Submission 25-2, no page numbers; Also see Submissions: 38, 42

[116] Submission 25-2, no page numbers.

[117] See for example Submissions: 37, 63.

[118] Submission 42, p. 3.

[119] See for example Committee Hansard: Lucy Savage, 18 September 2024; Submissions: 7, 19, 47, 60.

[120] Committee Hansard: Lucy Savage, 18 September 2024.

Given the valuable role of nurses, the evidence presented to the committee proposed for improving their education and training regarding endometriosis.[121] These training or professional development activities can include topics on detecting early signs of endometriosis and ordering the appropriate scans or imaging services, and more women's health relevant topics, among others, that would be helpful in creating a triage approach. As part of the NAPE, a course was developed by the Australian College of Nursing 'to provide the student with the necessary theoretical knowledge to improve how they assess and manage endometriosis and pelvic pain in the clinical setting.'[122] Endometriosis Australia recently launched its first 15 scholarships for nurses, especially for those in rural and regional areas, to attend the course.[123]

Furthermore, in an endometriosis or pain clinic or centre set up, nurses can lead the triage and/or act as nurse coordinators. In their submission, Professor Hull stated that while patients are waiting for their appointments with specialists, nurses can 'provide patient education and support through one-on-one or group programs.'[124] Additionally, in their presentation to the committee, Ms Campbell, the Endometriosis Nurse Coordinator at the JAECE, shared that in their set-up patients can make self-referrals and nurses in the clinic will then request GPs to 'provide the onward referrals for Medicare purposes.'[125]

The evidence provided to the committee supports the creation of endometriosis or more pain clinics in public hospitals across the state. These clinics are perceived to address and potentially minimise presentations to hospital emergency departments by better managing endometriosis related symptoms, especially complex pain. The evidence presented to the committee also proposed a multidisciplinary team to work in these endometriosis and pelvic pain clinics, and that the facility be open all the time. Nurses are seen as all but essential in these clinics as they can, given appropriate and substantial training, serve as contact points for patients and assist GPs in IUD insertion. Most of all, nurse specialists can be a first point of contact, lead the treatment, and management triaging of people suffering from endometriosis.

Non-medical support platforms

The complexity of diagnosing, treating, and managing endometriosis, given the varying symptoms on persons who have it, and the associated personal, economic, and social impacts to individuals and society, necessitates support beyond the healthcare systems. The evidence presented to the committee notes that supportive families and peers help individuals suffering from endometriosis navigate through the journey and decreases feelings of isolation when endometriosis associated symptoms are dismissed.[126] In the Commissioner for Children and Young People - Period Justice Working Group' presentation, Ms Caceres-Galvez, one of the members of the group implied that conversations of pelvic pain among friends increases awareness and acceptance of the individual going through the condition.

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[121] See for example Submissions: 15, 57, 60.

[122] Australian College of Nursing, *Endometriosis and Pelvic Pain*, Australian College of Nursing website, 2025, accessed 22 January 2025.

[123] Committee Hansard: Endometriosis Australia, 30 October 2024.

[124] Submission 34, no page numbers.

[125] Committee Hansard: Endometriosis Australia, 30 October 2024, p. 352.

[126] See for example Committee Hansard: Georgia Gosse, 10 July 2024; Berri hearing (Jesse Lang), 12 June 2024; Lucy Savage, 21 September 2024; Submissions: 51, 63.

> I have recently gone through a bit of a journey around pelvic pain and going to a doctor and trying to find out what it is. I remember I was with one of my friends and I was like, 'I feel horrible. I feel like this,' and they will say, 'Based on all the things you tell me, I think you should go and see a doctor… If you can have those conversations that you would have with just with your female friends in open friendship groups, it means that all those other people who usually would be excluded from those conversations know that is happening and then with their other friendship groups they know how to be more aware and more accepting.[127]

Some individuals living with endometriosis receive less support and understanding from family (details in Section 9).[128] In her presentation to the committee, Ms Gosse acknowledged the value of her family's support.

> I have a supportive family with whom I still live and who have been by my side this entire time. This is not afforded to everyone. When you hear some of the challenges, I have experienced I want you to remember the fortune within my context.[129]

Accordingly, the evidence given to the committee finds it essential to provide support to carers, families, partners, and peers of individuals living with endometriosis.[130] Personal relations can be further supported by reinforcing their knowledge and awareness about endometriosis, its impact to individuals suffering from the disease, and pathways to diagnosis, treatment, and management.[131]

A platform or space where support persons can join people living with endometriosis and exchange experiences and thoughts is also a welcomed support mechanism.[132] PPFA is one of these initiatives offering these support frameworks. In their presentation, PPFA highlighted PPEP Talk® Next Steps session where students who want to have their parents or families more involved in understanding menstrual education can come in. Ms Nielsen, the National PPEP Talk®, Manager described 'online sessions with Susan (Dr Susan Evans, Executive Chair of PPFA) for free once every two months, and it is a deeper dive into everything we have spoken about with endometriosis and pelvic pain.'[133]

Outside an individual's inner circle, a community of individuals living with endometriosis and/or advocates for better diagnosis, treatment, and management of the disease were identified as invaluable support systems. The evidence presented to the committee noted that information from advocacy groups and online educational and social platforms that provide the latest information and encourage communication around endometriosis are useful sources of updates and learnings from experiences, that gives some level of validation and assurance to

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[127] Committee Hansard: Commissioner for Children and Young People (Valeria Caceres-Galvez), 10 July 2024, p. 148.

[128] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Rochana Watkins, 10 July 2024; Submissions: 60, 70.

[129] Committee Hansard: Georgia Gosse, 10 July 2024, p. 139.

[130] See for example Committee Hansards: PPFA, 5 June 2024; Commissioner for Children and Young People, 10 July 2024; Submission: 61.

[131] See for example Committee Hansard: Thrive Family Practice, 28 August 2024; Submissions: 61.

[132] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; Endometriosis Australia, 30 October 2024; Submissions: 72, 80

[133] Committee Hansard: PPFA (Michelle Nielsen), 5 June 2024, p. 60.

individuals with endometriosis. Examples of these social groups or platforms are Endometriosis Australia,[134] EndoZone,[135] Endo Support SA[136], QENDO Inc,[137] and Australian Coalition for Endometriosis (ACE),[138] among others.

Relevant assistance to these advocacy groups and social initiatives is needed to continue the support they provide to persons living with endometriosis. The evidence provided to the committee mostly mentioned funding and grants from different stakeholders, generally from government bodies to sustain the delivery of services.[139] At the moment, relevant support from the Commonwealth Government in this area includes funding for Australian Coalition for Endometriosis to 'drive improvements and support in the endometriosis community[140] and a grant to QENDO Inc to 'develop a national endometriosis mentor program to support those newly diagnosed with endometriosis. [141]

Overall, personal relations, advocacy groups and social initiatives play an important role in the management of endometriosis. The support from personal relationships lessens the feeling of isolation among persons with endometriosis as they experience the different impact of the disease, and as they steer through diagnostic, treatment, and management options. Outside the personal circle, advocacy and social support groups are also a significant source of assistance for individuals living with endometriosis. This cohort not only communicate the latest developments on endometriosis and related matters, but also provides space for insightful exchanges of experiences with similar individuals living with endometriosis and experts, and provides a forum of recognition and validation of the symptoms. For these reasons, the evidence received by the committee pointed out the need to support personal and social groups to further contribute to a better quality of life for individuals suffering from endometriosis.

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[134] Committee Hansard: Endometriosis Australia, 30 October 2024; Submission: 46.
[135] Committee Hansard: Robinson Research Institute, 15 May 2024; Submission 34.
[136] Committee Hansard: Christie Nancarrow, 19 June 2024.
[137] Submissions: 16, 16b.
[138] Submissions: 5, 17, 17b.
[139] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Submission: 5.
[140] DHAC, *Record action on endometriosis continues in 2024.*
[141] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 5.

9. BARRIERS TO DIAGNOSIS, TREATMENT, AND MANAGEMENT OF ENDOMETRIOSIS

The long delay to diagnosis and the numerous visits to medical practitioners alongside trying multiple treatment options require an examination of the barriers to the diagnosis, treatment, and management of endometriosis in South Australia. The evidence presented to the committee indicated five main barriers towards the holistic approach towards endometriosis management in order to provide better health outcomes to individuals living with the condition. These are 1) the normalisation of pain; 2) timely access to and availability of health and medical professionals and services; 3) cost; 4) knowledge, expertise, and attitude of health and medical providers; and 5) education and health literacy among adolescents and families or carers.

9.1 Normalisation of pain

The normalisation of pain in relation to endometriosis is a situation where people are told that the pain they experience is normal as 'it falls within the range of what is normal for most people and is nothing to worry about.'[1] It becomes an issue when the person experiencing pain feels it is at an unusual level and is changing significantly. The evidence provided to the committee articulates how pain normalisation bars the timely, appropriate, and sufficient diagnosis, treatment, and management of endometriosis.[2]

The evidence received by the committee identified four interrelated reasons why normalisation of pain happens. First, individuals with endometriosis experiencing period and pelvic pain, would personally assess their own condition as common, based on conversations with and experiences of families and peers.[3]

Second, and one that compounds the first reason, is the lack of adequate knowledge on what constitutes normal period and pelvic pain by people living with endometriosis,[4] family and friends,[5] and relevant medical practitioners.[6] As an outcome, pain is normalised. Section 12 discusses further the necessary education for these cohorts in order to address the impact of the lack of awareness and education.

> As part of our focus groups, we asked participants to send in photos that represented their experience of living with endometriosis… They also highlighted a number of really key challenges. They spoke about the normalisation of symptoms, and that occurred at multiple levels: the individual not knowing what's normal, what's not; friends and family; and then at times healthcare providers really normalising period pain and the symptoms they were experiencing.[7]

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[1] EndoZone, *Pain normalisation*, EndoZone website, no date, accessed 27 January 2025.

[2] See for example Committee Hansard; Sonographers, 1 May 2024; Submissions: 8, 20.

[3] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Berri Hearing (Elizabeth Eske), 12 June 2024; Associate Professor George Condous, 10 July 2024; Rochana Watkins and Shannon Watkins, 10 July 2024; Finance Sector Union, 16 October 2024; Submissions: 6 ,9, 14, 16, 37.

[4] See for example Committee Hansard: Berri hearing (Julie Ahrens, Amara Turner); Submissions: 18, 37.

[5] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Berri Hearing (Julie Ahrens), 12 June 2024; Submissions: 9, 70, 74.

[6] See for example Committee Hansard: Berr hearing (Kaye Schober, Elizabeth Eske), 12 June 2024; Submissions: 27, 37, 83.

[7] Committee Hansard: Robinson Research Institute (Dr Beck O'Hara), 15 May 2024, p, 38.

Lastly, and related to medical professionals' lack of knowledge about endometriosis associated symptoms, is the lack of understanding and empathy towards people suffering from endometriosis.[8] This lack of ability to appreciate the concerns of people with the condition and try to understand and respond to them accordingly, is exhibited in medical providers' downplaying the pain and discomfort that persons living with endometriosis experience,[9] that in turn, leads to the dismissal of their concerns.[10] Evidence presented to the committee referred to this response from medical practitioners as gaslighting.[11]

> In my particular case, I have been told to see a mental health professional to determine if my pain is real, or if they can just put me on certain medications and I can 'put up with it', or that it was all in my head.[12]
>
> … the most troubling thing in endo and adeno warrior space is medical gaslighting. Medical gaslighting refers to the dismissive and invalidating behaviour exhibited by healthcare providers towards patients. We are constantly accused of lying, constantly accused of just wanting the drugs, told to 'Toughen up, Princess. Just be grateful it's not cancer'…[13]
>
> It's not just one GP who they see; they see multiple. They also hear things like normalisation of their pain, 'Well, it's just a woman's lot in life. Period pain is normal. It's just something you have to put up with.' Finally, they also talk about the fact that their pain is downplayed. It can't be as bad as they say it is. You're just trying to get out of PE or some other activity you don't want to do.[14]

There were different insights from the evidence given to the committee in terms of the role of the medical practitioner's gender in the normalisation of period and/or period pain. Some of the evidence articulated that the medical professional's gender did not matter when it comes to pain normalisation in contrast to the lack of knowledge about and training in dealing with period and/or pelvic pain.[15] In her presentation, Ms Han, an individual living with endometriosis and a sonographer from Berri, stressed that the training of medical service providers has more weight in how they respond to presentations of pelvic and/or period pain. She said that it was a male GP who recognised her pain, and that female GPs might have more tendency to normalise the pain based on their experience.

There was also evidence provided to the committee indicating that gender has a significant role in the normalisation of pain.[16] In presenting to the committee, Dr Halt, explained that the impact of gender bias goes beyond being dismissed in emergency departments for

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[8] See for example Committee Hansards: Berri Hearing (Jesse Lang), 12 June 2024; Lucy Savage, 18 September 2024; Submissions: 8, 19.

[9] See for example Committee Hansard: Lucy Savage, 18 September 2024: Submissions: 8, 14.

[10] See for example Committee Hansards: Berri Hearing (Jesse Lang, Kaye Schober), 12 June 2024; Lucy Savage, 18 September 2024; Submissions: 22, 24, 25-2, 37.

[11] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Deanna Flynn Wallis 19 June 2024; Submissions: 72, 73.

[12] Committee Hansard: Christie Nancarrow, 19 June 2024, p. 120.

[13] Committee Hansard: Deanna Flynn Wallis, 19 June 2024, p. 127.

[14] Committee Hansard: Dr Jane Chalmers, 10 April 2024; p. 2.

[15] See for example Committee Hansards: Berri Hearing (Jenny Han), 12 June 2024; Christie Nancarrow, 19 June 2024.

[16] See for example Committee Hansards: RANZCOG, 10 July 2024, Dr Monique Kanters, 18 September 2024; Dr Collin Weatherill, 21 October 2024; Submission: 83.

presentations of pain. She stated that it ‘actually forms real barriers to the use of innovations and technologies and access to medications down the line as well.’[17]

The normalisation of period pain is still present in in modern society.[18] Associate Professor Condous emphasised that as pain normalisation continues to exist, ‘effectively young women, young girls, tend to maybe conceal or underplay the symptoms they are having, either with their friends or their family, because they feel it's not the right thing to talk about.’[19] As noted in Section 6, pain normalisation affects the emotional and mental health of people living with endometriosis as it makes them doubt or question themselves.[20]

Pain normalisation also makes the discussion of period and pelvic pain a taboo, that discourage further conversation of the matter in the personal[21] and social[22] arenas. Furthermore, pain normalisation brings stigma to individuals having such conditions.[23] The effect of menstruation and period related pain as somehow an off-limits topic in workplaces; this is detailed in Section 10. Under these circumstances, there are further barriers that delays formal diagnosis of endometriosis that is necessary to create a treatment and management pathway.

The evidence presented to the committee noted that an effective and efficient way to combat endometriosis related pain normalisation by individuals with endometriosis, their families and friends, and medical service providers is through appropriate and customised information, education, and communication materials and initiatives.[24] PPFA’s PPEP®Talk is referred to in the evidence presented to the committee, to be providing these services to all cohorts.[25] Specific professional development courses or workshops for health and medical practitioners, particularly GPs, sonographers, and physiotherapists, are also mentioned in the evidence provided to the committee, to mitigate the dismissive attitude and behaviour by health and medical professionals, particularly doctors.[26] These initiatives are discussed in detail in Section 10.

To summarise, pain normalisation is a key barrier to the timely, appropriate, and adequate diagnosis, treatment, and management of endometriosis. Pain is normalised through self-normalisation that is often based on experiences and discussions with personal relations and lack of correct and sufficient knowledge about endometriosis by persons living with the condition, their family and peers, as well as medical practitioners.

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[17] Committee Hansard: RANZCOG (Dr Magdalena Halt), 10 July 2024, p. 220.

[18] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Robinson Research Institute, 15 May 2024; Berri hearing (Kaye Schober), 12 June 2024; Submissions: 22, 24, 27.

[19] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 142.

[20] See for example Committee Hansards: Berri hearing (Jesse Lang), 12 June 2024; Christie Nancarrow, 19 June 2024; Deanna Flynn Wallis, 19 June 2024; Ms George Gosse, 10 July 2024; Submission: 41.

[21] See for example Committee Hansard: Commissioner for Children and Young People, 10 July 2024.

[22] See for example Committee Hansards: Robinsons Research Institute, 15 May 2024; Commissioner for Children and Young People, 10 July 2024; Lucy Savage, 18 September 2024; Submissions: 41, 43, 55, 69.

[23] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Associate Professor George Condous, 10 July 2024; Submission: 20.

[24] See for example Committee Hansards: Associate Professor George Condous, 10 July 2024; Lucy Savage, 18 September 2024; Submissions: 72, 73.

[25] See for example Committee Hansards: Associate Professor George Condous, 10 July 2024; Commissioner for Children and Young People, 10 July 2024.

[26] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Sonographers, 1 May 2024.

Normalisation of pain can occur when medical professionals belittle and dismiss claims of pain and inconvenience by persons suffering from endometriosis. The evidence received by the committee was divided in terms of the role of gender in the normalisation of pain. It has been suggested that pain normalisation is an obstacle to getting diagnosis, treatment, and management of endometriosis because individuals who are living with the disease doubt themselves, preventing them from speaking more openly about it.

There is also concern over being stigmatised for having endometriosis. The normalisation of pain also leads to making the topic on menstruation and endometriosis taboo. Appropriate, sufficient and tailor-made information, education, and communication materials and sessions and relevant continuing professional development courses and workshops for individuals living with endometriosis, their families and peers, and health and medical service providers are mechanisms to address pain normalisation.

9.2 Cost

Cost can hinder providing adequate, timely and holistic care to individuals suffering from endometriosis, and can be brought about by four interconnected factors. These are multiple treatments and visits to medical practitioners, rebates for procedures and services in the MBS, rebates for medicines in the PBS, and access to private health insurance.

The evidence received by the committee stressed the expenses related to seeking multiple diagnosis, treatment, and management options as obstacles to diagnosis, treatment, and management of endometriosis.[27] Armour et al stated that individuals with endometriosis spend 'roughly $30, 000 per person with endometriosis per year.'[28] The evidence submitted to the committee reflects a similar amount,[29] with some mentioning annual out-of-pocket costs relative to endometriosis ranging from $5,500 – 50,000.[30]

Being in regional, rural, and remote areas increases the cost of accessing the necessary diagnostic, treatment, and management options for endometriosis.[31] The evidence received by the committee underlined logistical costs, such as transport, accommodation and food, to add to expenses of obtaining health and medical services.[32] There is also the potential costs for carers to mind children whilst away as well as the loss of wages. If the person living with endometriosis be accompanied by working family members or friends, then there is the additional cost for that person.[33]

The evidence presented to the committee also indicates that some of the medications or treatment therapies are expensive.[34] Since some people living with endometriosis might take

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[27] See for example Committee Hansard: Sonographers, 1 May 2024; Submission: 2.

[28] M Armour, et al., 'Lessons from implementing the Australian national action plan for endometriosis, p. C30.

[29] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Professor Jason Abbott, 11 September 2024; Stacey Seedon, 18 September 2024; DHAC, 25 September 2024.

[30] See for example Submissions: 14, 24, 36, 38.

[31] See for example Committee Hansard: Berri hearing (Julie Ahrens), 12 June 2024; Submission: 85.

[32] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Berri hearing (Jesse Lang), 12 June 2024; YPPPC, 13 November 2024; Submissions: 37, 38, 54. 60.

[33] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Lucy Savage, 18 September 2024; Submission: 46.

[34] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Rochana Watkins, 10 July 2024; Submission: 54.

these medications for a long period or repeatedly, they incur significant costs. For instance, pelvic floor Botox for pelvic pain is not covered by the PBS as it is considered as a cosmetic treatment.[35] Ryeqo, another hormonal medication to manage endometriosis,[36] is produced by Gedeon Richter, that made a submission for the consideration to the Pharmaceutical Benefits Advisory Committee (PBAC) last March 2024. PBAC has recommended Ryeqo be included by April 2024. The next step is for Gedeon Richter to lodged or submit a required set of documents. As of writing this report, there has been no progress in this area.[37] Furthermore, Professor Abbott's explained that the debate over low PBS rebates for hormonal treatment options is because these treatments were not specifically designed for endometriosis treatment but are also prescribed to those people who simply need contraception.[38]

As people with endometriosis might repeatedly access varied health and medical services and procedures, the low MBS rebates for certain services and procedures adds to the financial burden of the person. The evidence presented to the committee enumerated that in terms of services and procedures, the following factors are partly responsible for the high cost of endometriosis treatment and management:

- limited and no increase in the access to relevant allied health services in the chronic disease management plan;[39]
- limited and no increase in the rebates for allied health services[40] – even a reduction in the funding for psychological services[41] and the exclusion of dietetics in the chronic disease management plan;[42]
- low Medicare rebates for laparoscopic surgery and hospital stay after surgery;[43] and
- low Medicare rebates for pelvic floor ultrasound, with no additional remuneration for TVUSS;[44]

The evidence also indicates that the low and lack of Medicare rebates for health and medical professionals' services adds to the high cost of endometriosis treatment and management. The low MBS rebates allocated for consultations with gynaecologists,[45] GPs[46], and pain specialists[47] increases the out-of-pocket cost borne by individuals living with endometriosis.

For GPs, the evidence provided to the committee implied that regardless of the consultation time spent by GPs to talk to their patients, the remuneration is the same.[48] For this reason, GPs would usually spend an average of 15 minutes for consultation as a longer consultation

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[35] See for example Submission 36.
[36] See Submission 67.
[37] Australian Government, *Relugolix with estradiol and with norethisterone acetate*, The Pharmaceutical Benefit Scheme Website *Medicine Status,* accessed 30 January 2025.
[38] Committee Hansard: Professor Jason Abbott, 11 September 2024.
[39] See for example Submissions: 37, 38, 52, 70.
[40] See for example Submissions: 36, 37, 38.
[41] See Submission: 38.
[42] See Submission: 38.
[43] See Submission 70.
[44] See for example Committee Hansards: Sonographers, 1 May 2024: Associate Professor George Condous, 10 July 2024; Submission: 37.
[45] See for example Submissions: 16, 16b, 33, 42.
[46] See for example Submissions: 9, 36, 65.
[47] See for example Committee Hansards: SHINE SA, 10 Jully 2024; YPPPC, 13 November 2024; Submission 36.
[48] See for example Committee Hansards: SHINE SA, 10 July 2024; Thrive Family Practice, 28 August 2024; Submissions: 9, 52.

would decrease the number of patients GPs can see in a day.[49] Since longer consultations are often required for endometriosis, as it is a complex chronic disease, the evidence received by the committee indicates that individuals suffering from endometriosis might not have long consults with GPs.[50]

Further, the evidence articulates that there is a low rebate for GPs to do IUD insertions, a common hormonal therapy prescribed to individuals with endometriosis.[51] The remuneration is considered insufficient considering the fee that GPs pay to train for the procedure, 'the instruments/resources needed to make the service, the time required for the procedures and the nursing support pre- and post-procedural care'.[52] The evidence provided to the committee also indicates that GPs' participation in a multidisciplinary team of carers receives no remuneration.[53]

The presentation from DHAC, however, showed evidence that MBS rebates for GP consults are time-tiered, with longer consultations receiving higher rebates than short consults. (See Annex 17.5). The same presentation also stressed that the participation of GPs in multidisciplinary case conferences, including the preparation of the chronic disease management plan, has an equivalent MBS rebate that differs based on the length of the GP's participation in the case conference (See Annex 17.5). Additionally, DHAC's presentation articulated that pelvic ultrasound referred by a GP, has an MBS item, hence there is a rebate.[54] MRIs had to be requested by a gynaecologist to receive rebates.[55]

Similarly, the evidence received by the committee presented the same concern for the consultation time with specialist such as gynaecologists and pain specialists. The evidence provided to the committee notes that despite endometriosis being a gynaecological concern, the MBS allocation for gynaecological consults regardless of time spent is the same.[56] Additionally, the evidence submitted to the committee stated that gynaecologists' participation in the multidisciplinary team of care, is unfunded in the MBS.[57]

As gynaecologists' consultation times are not time-tired, the Commonwealth Government has announced the increase in the MBS rebate for long first and follow-up consultations with gynaecologists, beginning 1 July 2025. From the standard rate of $95.60, the consultation fee for longer initial gynaecologist consultation will be $168.60. There will also be an increase from $48.05 fee for subsequent consultations to $84.35.[58] Furthermore, in terms of rebates for specialists' participation in a multidisciplinary team, the DHAC's presentation to the committee highlighted that there are several MBS refunds for the engagement of specialists and consultant physicians in a multidisciplinary team. (See Annex 17. 5).

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[49] See for example Committee Hansard: Thrive Family Practice, 28 August 2024; Submission: 37.
[50] See for example Committee Hansard: Sonographers, 1 May 2024; Submissions: 10, 20, 25-2.
[51] See for example Committee Hansard: Dr Jane Chalmers, 10 April 2024; Submissions: 37, 79.
[52] Submission 37, no page numbers.
[53] See for example Committee Hansard: Adelaide Pelvic Pain Network, 10 July 2024; Submissions: 38, 52.
[54] Committee Hansard: DHAC, 25 September 2024.
[55] See Submissions: 37, 79.
[56] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; RANZCOG, 10 July 2024; Submissions: 16, 33
[57] See for example Committee Hansard: RANZCOG, 10 July 2024.
[58] Department of Health and Aged Care, *Historic Medicare changes for women battling endometriosis* [media release], DHAC, 10 May 2024, accessed by 17 May 2024.

Challenges in accessing timely and adequate care (discussed further in the next sub-section) due to the long waiting list in the public health system drives people with endometriosis to take out private health insurance to access private health care. The evidence presented to the committee articulates that having private health cover expedites access to necessary treatment and management options. [59] Getting timely diagnosis, treatment and management options, reduces the chance of endometriosis getting worse, hence facilitating better health outcomes for people suffering from the disease.

In situations where primary specialised services are not available in the public health system, the evidence provided notes that people with endometriosis who do not have or cannot afford private health insurance, have further delays in getting diagnosis, treatment, and management.[60] Nevertheless, as private health insurance can be expensive, this adds to the cost of managing endometriosis for an individual.[61]

> … I have always had the benefit of private health care. I grew up with private health insurance provided by my parents and when I was able to afford my own, I bought it. I have not encountered the delays in accessing the care that I needed as are often encountered in the public health system…[62]
>
> Twenty-three now and jaded with a system that is supposed to support me, a system I work for but can't access because my disease is not visible to the eye. Told that I 'rort' the system because I know how it works. But in reality, unless I continue to pay for private insurance that I can barely afford, I can't access proper help. Let alone practitioners who believe me.[63]

Noteworthy, some evidence received by the committee stresses that private health insurance is no longer enough to cover the increasing medical expenses associated with endometriosis diagnosis, treatment and management.[64]

> There is a significant cost to accessing private treatment even with private health insurance. For a start there is the cost of the private health insurance policy and then it doesn't cover out-of-hospital appointments and treatments with a gynaecologist.[65]
>
> It shocks me that even paying the highest private health cover, does not sustainably support Endometriosis patients which is why many are unable to access health care for it.[66]

In formal correspondence with the Private Health Care Australia, Mr Harris, Director of Policy and Research, explains that the main mechanism to address the high out-of-pocket costs

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[59] See for example Submissions: 21; 24, 47, 63, 83.
[60] See for example Submissions: 8, 27, 47, 49, 50, 63, 69, 83.
[61] See for example Submissions: 47, 59, 83.
[62] Submission 47, no page numbers.
[63] Submission 59, no page numbers.
[64] See for example Submission: 14, 36, 38, 70, 76, 80.
[65] Submission 70, p. 4.
[66] Submission 80, no page numbers.

involved in the diagnosis, treatment, and management of endometriosis is to contract with doctors. However, at present 'it is up to the doctor how much they charge, and medical specialists can charge whatever they want under Australia law, and there is almost no transparency or ability for consumers to shop around.'[67] Moreover, in relation to the high costs of health insurance Mr Harris stated that increased accessibility of private health insurance by individuals living with endometriosis can be facilitated through the following actions:

- reducing the level of regulation for private health insurance in Australia;
- reducing the prices of medical devices;
- encouraging more out-of-hospital care;
- discouraging low value care; and
- removing hospital subsidy programs.[68]

Overall, cost is a significant barrier to accessing diagnoses, treatment, and management of endometriosis. Individuals suffering from the condition incur high out-of-pocket costs from seeking and trying multiple treatments and multimodal services, which either has no allocation or low rebates in the MBS or PBS. In an attempt to receive customised, sufficient, and timely care, individuals with endometriosis also take-out private health care insurance. It becomes an additional cost as private health insurance is expensive, and people living with endometriosis who have private health insurance may still sustain significant out-of-pocket costs for medical treatment and services, including medical practitioners' fees.

9.3 Lack of and limited health and medical services and providers

The concern around access and availability of health and medical services and professionals is emphasised in the evidence presented to the committee.[69] The evidence received indicates that there are setbacks to access and availability of essential health and medical services at each stage of the treatment and management pathway.[70]

Relative to diagnosis, the evidence highlights the lack of imaging centres to perform TVUSS[71] and a lack of specialist sonographers to perform the scan across the state[72] The long waitlist to see a gynaecologist in the public health system[73] leads to more waiting time to get a laparoscopy to diagnose and/or excise endometriosis.[74] The long waitlist to access clinical confirmation of endometriosis is indicative of the limited gynaecologist or pain specialists, at least in the public health system.[75] Without a clinical confirmation of having the diseases,

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[67] Ben Harris (personal communication, 28 November 2024), p. 1

[68] Ben Harris (personal communication, 28 November 2024), p. 2.

[69] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Sonographers, 1 May 2024; Robinson Research Institute, 15 May 2024; Associate Professor George Condous, 10 July 2024; Professor Jason Abbott, 11 September 2024.

[70] See for example Committee Hansards: PPFA, 5 June 2024; Commissioner for Children and Young People, 10 July 2024; DHAC, 25 September 2024.

[71] See for example Committee Hansards: Sonographers, 1 May 2024; Associate Professor George Condous, 10 July 2024; Submission: 4.

[72] See for example Committee Hansards: Sonographers, 1 May 2024; Berri hearing (Jenny Han, Jesse Lang), 12 June 2024; Associate Professor George Condous, 10 July 2024.

[73] See for example Committee Hansards: Dr Monique Kanters, 18 September 2024; JAECE, 30 October 2024; Submissions: 21, 25-2, 26, 30, 32.

[74] See for example Committee Hansard: SHINE SA, 10 July 2024; Submissions: 31, 36, 38.

[75] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024; Dr Monique Kanters, 18 September 2024; Submissions: 32, 34, 37, 38.

persons suffering from endometriosis are in limbo as to which treatment and management pathways to pursue, that further impedes better health outcomes.[76]

The evidence presented to the committee indicates the limited number of people with endometriosis receiving and having a chronic disease management plan.[77] This could mean that most people with endometriosis are still subjected to a fragmented health care approach. One potential reason for this lack of access to a chronic disease management plan is the lack of awareness of health and medical professionals of this treatment and management mechanism, particularly GPs. This is discussed further in the next sub-section.

The lack of or limited access to appropriate and adequate health and medical providers and services is apparently more pronounced in regional and rural areas.[78] Living in regional and rural areas means absence of or more limited availability of diagnostics tools such TVUSS and specialist sonographers,[79] specialists, gynaecologists and pain specialists,[80] allied health professionals,[81] and the multidisciplinary care approach.[82] In Section 8, doubts over the effectiveness and efficiency of the multidisciplinary model of care surfaced due mainly to the lack of health and medical providers available to establish a team. Moreover, the committee heard of evidence regarding the lives of people living with endometriosis to be at stake partly because they accessed treatment in the city, travel back to the region where the options for care after surgery is limited. Two of these cases are presented in Table 2.

Table 2. Location, access, and lives at risk

'Really difficult being a Riverlander'
… It got really difficult being a Riverlander because it was the beginning of an April holiday that then led into the school holidays, so she was sent home after the surgery… we asked if they thought it was okay for her to come home or whether we should stay in Adelaide for a while, and they said they thought that she would be fine. She came home (we were living in Loxton at the time) and she was clearly very, very unwell… So we saw a doctor at the Loxton clinic, who was horrified that she was back in the Riverland in the state she was in…He was concerned that she might have clots and sent us to the Berri Hospital on what I reckon must have been Good Friday. The people who do the ultrasounds and scans were called in… and that wasn't a good experience… she did have clots, and she was in trouble. Fortunately, the doctor in Loxton had insisted that we go, and we had advocated, and she got it tested, and then the doctor rang us at home and said she immediately had to go onto the anti-clotting injections …[83]

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[76] See for example Submissions: 41, 42, 44.

[77] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; RANZCOG, 10 July 2024.

[78] See for example Committee Hansard: Georgia Gosse, 10 July 2024; Endometriosis Australia, 30 October 2024; Professor Jason Abbott, 11 September 2024.

[79] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024; Sarah Coshan, 18 September 2024.

[80] See for example Committee Hansards: Berri hearing (Julie Ahrens, Jenny Han), 12 June 2024; Sarah Coshan, 18 September 2024; Eloise Zanoni, 18 September 2024; Emma Dempster, 18 September 2024.

[81] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024; Sarah Coshan, 18 September 2024; Eloise Zanoni, 18 September 2024.

[82] See for example Committee Hansards: Berri hearing (Jenny Han, Amara Turner), 12 June 2024; Eloise Zanoni, 18 September 2024.

[83] Committee Hansard: Berri hearing (Julie Ahrens), 12 June 2024, pp. 80-81.

'Travelling 500 kilometres from Adelaide back to Mount Gambier'

The day after the laparoscopy, living in a rural town, I had to travel 500 kilometres from Adelaide back to Mount Gambier and was told to rest up for a couple of weeks. I was in too much pain to move, shower or eat, or even to breathe. Throughout the day on Friday, the day after, my abdominal pain continued to get worse and worse until about 4pm when it became so intense I started to scream uncontrollably. I sat on the floor of the ER for what felt like an hour, but was really only 20 minutes, screaming and crying out for someone to help me.

Over the next three days, I travelled in two ambulances after waking up in the middle of the night screaming in the same unbearable pain. Finally, at 2am on Sunday, I was back in the emergency room and the female overnight doctor suggested my pain might be the Mirena… It turned out I had been experiencing contractions since Wednesday as my body rejected the Mirena. The overnight doctor had to contact my specialist to get permission to remove it but, given she lives in Adelaide, we couldn't get hold of her. Ultimately, I told the doctor to please just get rid of it, to which she responded, 'I've never actually removed a Mirena'—brilliant. She gave me laughing gas, on top of everything I was already on, and ripped the Mirena out. This was, I think, the most pain I have ever felt in my entire life. I was discharged and went home to continue to be physically sick. I continued to experience contractions throughout the night and called an ambulance for the third time in two days. They said there was nothing they could do and that my body was still adjusting. [84]

The evidence presented to the committee attributes the lack of and limited access to health and medical services and practitioners in regional and rural areas, to the shortage of workforce to cater to the needs of people suffering from endometriosis.[85] Labour shortage within the public health sector in regional and rural areas is linked to the lack of incentivisation for health and medical service providers, such as resettlement fees.[86] Furthermore, health and medical professionals seem disinterested in working outside the metropolitan area because of the limited access to and availability of continuing professional development courses and workshops. Under the circumstances, individuals with endometriosis, who are residing in regional and rural areas, have to exert extra effort and shoulder higher costs in getting diagnosis, treatment and management for endometriosis.[87]

In conclusion, the absence of or shortage of health and medical services and providers hinders the holistic treatment and management of endometriosis. The situation is most felt in regional and rural settings. Individuals living with endometriosis who reside in these areas, experience more challenges to access and availability of adequate, appropriate, and timely treatment and management due to a constrained workforce.

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[84] Committee Hansard: Dr Monique Kanters, 18 September 2024, p. 267.

[85] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024; Associate Professor George Condous, 10 July 2024; Georgia Gosse, 10 July 2024; Professor Jason Abbott, 11 September 2024; Endometriosis Australia, 30 October 2024; Submission: 4.

[86] See for example Committee Hansards: Berri hearing (Jenny Han), 12 June 2024; Submission: 4

[87] See for example Committee Hansards: JAECE, 30 October 2024; YPPPC, 13 November 2024; Submissions: 42, 78.

9.4 Shortcomings of health and medical practitioners

Evidence submitted to the committee notes that health and medical practitioners can display a lack of a) empathy;[88] b) sensitivity in their action, especially when seeing adolescents;[89] and c) sufficient or updated knowledge about endometriosis.[90]

The evidence received by the committee, especially those from individuals who have endometriosis, expresses that medical professionals often doubted individuals' interpretations of their symptoms as endometriosis.[91] The phrases, 'it's all in your head' and 'it'/that's normal', and labelling expressed emotions by individuals who are suspected of having endometriosis, as 'dramatic', commonly appeared in the majority of the evidence given to the committee across all sectors.[92] As noted earlier, and in relation to pain normalisation, the term 'dismissed' surfaced in much of the evidence from people with endometriosis, to describe the reaction they received from clinicians they have consulted.[93]

> For my entire 18 years seeking treatment for endometriosis, I was repeatedly told by healthcare professionals (including gynaecologists) that my symptoms were initially cries for attention, psychomanifestations, and a sensitivity to normal teenage menstrual pain. This rhetoric followed me into my late 20s, along with new gaslighting. My decision to pursue a full hysterectomy and oophorectomy due to its highest rate of alleviating endometriosis symptoms, coupled with not wanting children was accredited to being "too young to know" what I wanted, and that I would change my mind when pain free.[94]
>
> Surely in the 21st century the medical profession should be able to listen and support women with their gynaecological journeys, provide excellent health advice and not give the impression or belief that we need to "Just Put Up With It and soldier on", or the impression that you are not "tough enough"[95]

The evidence submitted to the committee noted age as a factor to the lack of understanding from medical professionals towards individuals suffering from endometriosis.[96]

> I very clearly addressed to the GP my issues: painful and irregular periods, fatigue, nausea and concerns surrounding my hormones. I said, 'I think I have hormonal problems because of reason A, reason B and reason C,' to which she responded, 'Friendships are tricky and constantly changing at your age. I would say that's what you are experiencing.' The courage it had taken me to speak up was immediately

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[88] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Georgia Gosse, 10 July 2024; Submissions: 9, 18, 25-1.

[89] See for example Committee Hansard: Berri hearing (Julie Ahrens),12 June 2024; Submissions: 19, 24.

[90] See for example Committee Hansard: Berri hearing (Kaye Schober, Amara Turner), 12 June 2024; Submissions: 9, 17, 20, 24.

[91] Submissions: 14, 25-2.

[92] See for example Submissions: 25-2, 37.

[93] See for example: Committee Hansard: Berri hearing, 12 June 2024; Submissions: 26, 83.

[94] Submission 14, p. 3

[95] Submission 40, p. 2.

[96] See for example Committee Hansard: D Monique Kanters, 18 September 2024; Submission 21.

> crushed, and I felt that my symptoms were not being taken seriously because of my age.[97]

Aside from being doubted, the evidence presented to the committee notes the 'rushed' consultations gave individuals who presented with symptoms of endometriosis,[98] the feeling of 'giving a quick fix.'[99]

Other than empathy, the evidence presented to the committee articulates the lack of sensitivity among health and medical service providers, especially when dealing with young people suffering from endometriosis.[100] In her presentation to the committee, Ms Ahrens shared that her daughter was traumatised from her experience of TVUSS as she was not informed that the university student who would come in to observe the procedure was male.

> She said internal ultrasounds have traumatised her. She now… see[s] a psychologist and the medication she takes affects her mental health. She said she had a particularly traumatic experience at a women's clinic where she was asked if a student could come in… The procedure was underway and then the student walked in… she had agreed to have a student assuming it was a female. She said that was a really traumatic thing for a young woman—any woman—but at her particular time of life.[101]

Moreover, the evidence submitted to the committee also indicate that some medical service providers ask 'inappropriate' questions due to their lack of sensitivity towards their patients.[102] Again, age appear to be a factor for this behaviour by medical service providers, as they were mostly directed to adolescents.[103]

The perfunctory attitude and behaviour of some medical practitioners towards individuals living with endometriosis is somewhat attributed to the limited knowledge or lack of updated information regarding the disease.[104] The evidence provided to the committee articulates that when patients enumerate their symptoms, they do not feel listened to or understood.[105] In their presentation to the committee, Dr Kearney of Yorke Peninsula Pelvic Pain Clinic, stressed that most of what her team does when dealing with individuals with endometriosis is therapeutic listening. As most patients experienced dismissal from medical practitioners regarding their pain and symptoms, '… we are just acknowledging the patient's journey … as well as looking at ways in which they can manage their pain with our multidisciplinary team.'[106]

General practitioners are usually the first point of contact for people who suspect they have endometriosis or just for pelvic and period pain relief. While GPs might already be adept at

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[97] Committee Hansard: Dr Monique Kanters, 18 September, p. 266.

[98] Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Berri hearing (Kaye Schober), 12 June 2024.

[99] Committee Hansard: Berri hearing (Kaye Schober), 12 June 2024, p. 95.

[100] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Georgia Gosse, 10 July 2024; Submissions: 9, 18, 25-1.

[101] Committee Hansard: Berri hearing (Julie Ahrens, Julie), 12 June 2024, p. 82.

[102] See for example Committee Hansard: Berri hearing (Julie Ahrens), 12 June 2024, p. 80.

[103] See for example Committee Hansards: Berri hearing (Julie Ahrens, Elizabeth Eske), 12 June 2024; Emma Dempster, 18 September 2024.

[104] See for example Submissions: 20, 63, 79.

[105] See for example Committee Hansard: Commissioner for Young People, 10 July 2024; Submission: 81, 83.

[106] Committee Hansard: YPPPC (Dr Anna Kearney), 13 November 2024, p. 366.

managing complex medical cases, with the concern mentioned above, the evidence submitted to the committee emphasises the importance for GPs to receive further and regular education, training, and capacity-building to use for their practice.[107] SA Health Maternal, Neonatal and Gynaecology Strategic Executive Leadership Committee's submission states that GPs' knowledge about endometriosis varies, hence affecting how patients with the condition are treated.[108]

Moreover, the crafting of a multidisciplinary management plan is deemed challenging if GPs have limited knowledge and understanding of endometriosis and its symptoms, alongside, a lack of interest to further develop their endometriosis knowledge.[109] There is also the danger of GPs referring a patient to specialists who are likely lacking in terms of conducting proper investigations for endometriosis associated symptoms.[110]The existing continuous professional development courses for GPs and those proposed by the evidence presented to the committee is discussed in Section 11.

Increasing GPs knowledge of endometriosis and developments in regard to diagnosis, treatment, and management can encourage them to treat and manage the condition accordingly.[111] More than that, adequately educated and trained GPs will save people living with endometriosis money and time.[112] Accordingly, it will produce better health outcomes for these people, that in turn, will have a positive impact to country's health care system.[113]

There are drawbacks from health and medical service providers related to their attitudes and behaviours towards people with endometriosis. The evidence provided to the committee states that some health and medical practitioners are hesitant to acknowledge patients' reports of endometriosis related symptoms and/or are insensitive to patients' conditions causing the latter to feel dismissed, rushed during their consultations, and doubtful of themselves and their condition. Another shortcoming of health and medical service providers is their lack of or limited information about endometriosis and current diagnostic tools, treatment, and management options. This flaw is seen to contribute to pain normalisation and the lack of empathetic listening and understanding towards people with endometriosis. Creating a multidisciplinary care team is negatively affected if GPs have inadequate and outdated knowledge about the disease. Further education and upskilling for health and medical practitioners on endometriosis is therefore necessary.

9.5 Lack of education among young people, families, and peers regarding endometriosis

The evidence received by the committee presents that young people's lack knowledge about endometriosis is an obstacle to getting diagnosis, treatment, and management of their condition.[114] While some evidence presented to the committee articulated increased

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[107] See for example Submissions: 15, 25-2, 30, 38, 79.
[108] Submission 54.
[109] See for example Submissions: 25-2, 38.
[110] See for example Submissions: 9, 54.
[111] Submission 38.
[112] See for example Submissions: 12, 14, 25-2
[113] See for example Committee Hansard: Berri hearing (Jenny Han), 12 June 2024; Submission: 25-2
[114] See for example Submissions: 7, 10.

awareness about endometriosis,[115] this might not necessarily entail having correct and sufficient information about the condition.

One factor contributing to this scenario is that menstruation, a topic relevant to endometriosis, continues to be a taboo topic.[116] When young girls, women, and those AFAB raise concerns about period or pelvic pain and it is normalised either by families or health and medical practitioners, young people are unable to advocate for themselves due to the lack of adequate and correct information about menstruation.[117] With the long waitlist to see health and medical practitioners, especially in the public health system, equipping young people with correct and adequate education, can help them assess their health conditions,[118] potentially self-manage in the short term,[119] and have 'a set of language to be able to escalate through the health systems.'[120]

The evidence received by the committee also noted that it is challenging to provide young people with education regarding endometriosis when they are unfamiliar themselves of their menstrual cycle.[121] Menstrual education must be provided first to young people in order to have a better understanding of period and pelvic pain and endometriosis.[122] In addition, if young people have inadequate education or information regarding these matters, they could miss on 'simple things they can do themselves to reduce their pain; what might suggest that endometriosis might be present and when to look for help with a health professional.'[123]

As noted in Section 2, recent statistics have shown that 'by age 31, a higher proportion of women in the younger cohort had been diagnosed with endometriosis (9.2% of those born in 1989–95 compared with 6.9% born in 1973–78).'[124] Hence, it is essential for young people to get sufficient and accurate information and education regarding menstruation, what is 'normal' and 'not normal' period pain. Accordingly, educating young people would prevent disease progression and health deterioration through early detection.[125]

Given the impact that endometriosis has on personal and social relations, the evidence submitted to the committee also saw it necessary to educate families and friends of individuals, especially of young people, with endometriosis.[126] As noted earlier in this section, family members and peers lack the correct information about endometriosis that can lead to pain

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[115] See for example Committee Hansards: Adelaide Pelvic Pain Network, 10 July 2024; RANZCOG, 10 July 2024; Submissions: 33, 36.
[116] See for example Committee Hansards: PPFA, 5 June 2024; Commissioner for Children and Young People, 10 July 2024; Submissions: 41, 43.
[117] See for example Committee Hansards: PPFA, 5 June 2024; Commissioner for Children and Young People, 10 July 2024.
[118] See for example Committee Hansards: PPFA, 5 June 2024; Rochana Watkins, 10 July 2024; Submissions: 52, 54, 60.
[119] See for example Committee Hansard: Associate Professor George Condous, 10 July 2024; Submissions: 61, 69, 70.
[120] Committee Hansard: PPFA, 10 July 2024, p. 60.
[121] See for example Committee Hansards: PPFA, 5 June 2024; Commissioner for Children and Young People, 10 July 2024.
[122] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; PPFA, 5 June 2024; (4); Commissioner for Children and Young People, 10 July 2024; Lucy Savage, 18 September 2024; Endometriosis Australia, 30 October 2024.
[123] Committee Hansard: PPFA, 10 July 2024, p. 60.
[124] AIHW, *Endometriosis*.
[125] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; PPFA, 10 July 2024.
[126] See for example Committee Hansard: Georgia Gosse, 10 July 2024: Submission: 17.

normalisation.[127] The evidence provided to the committee articulates that the normalisation of the period and pelvic pain experienced by individuals, especially adolescents suffering from endometriosis, by family members and friends brings significant emotional and mental distress.[128] Being in this condition might discourage young people from seeking health and medical help, not to mention, that they might need older family members, such as guardians, to accompany them to consultations. Section 11 has more details on current and proposed information, education, and communication mechanisms for families and peers.

Notably, the evidence received by the committee articulates young people and their families' lack of awareness of relevant allied health service providers. This scenario was emphasised during the regional hearing held at Mount Gambier. The committee heard evidence that individuals with endometriosis were unaware that exercise physiologists, a helpful allied health service provider when dealing with pelvic pain, was present in their area.[129]

Overall, young people and their families and friends' lack of or limited education and information about menstruation, period and pelvic pain, and endometriosis will hinder adolescents' timely diagnosis, treatment and management of endometriosis. With correct and sufficient information and education on the matters, young people will be able to evaluate what's normal or not in relation to their menstruation, that in turn, will aid in deciding whether to see a doctor. Educating young people on menstruation, period and pelvic pain, and endometriosis will assist them in managing their conditions, while waiting to be seen by a doctor. Equipped with proper and adequate information on these matters will also help young people advocate for themselves and their peers. A key factor in young people seeking health advice concerning period and pelvic pain and endometriosis is well-informed family and peers.

Altogether, there are four major obstacles to getting holistic care for endometriosis, namely 1) normalisation of pain; 2) timely access to and availability of health and medical professionals and services; 3) cost; 4) knowledge and expertise among health and medical providers; and 5) lack of education among young people, families, and peers about endometriosis. These factors are interrelated and becomes more challenging to deal with for people suffering from endometriosis and living in regional and rural areas. The evidence presented to the committee stresses that 'no amount of medical intervention will change if women [people with endometriosis] are prevented from accessing care' that is appropriate and adequate and is received in a timely manner.[130]

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[127] See for example Submissions: 37, 43, 44, 61, 70.

[128] See for example Submissions: 70, 74, 79.

[129] See Committee Hansards: Sarah Coshan, 18 September 2024; Emma Dempster, 18 September 2024.

[130] Lancet, The, 'Endometriosis: addressing the roots of slow progress', *Lancet (London, England)*, 2024, 404(10460): 1279.

10. THE IMPACTS TO EMPLOYMENT AND WORKPLACE BEST PRACTICES AND SUPPORT

10.1 Decrease in productivity

As discussed in Section 2, endometriosis affects an individual's productive capacities. The evidence submitted to the committee, highlights the interconnected effects of endometriosis to paid work, which are absenteeism and presenteeism that affects an individual's capacity to finance their treatment and management pathways, often resulting in depriving individuals with endometriosis from achieving their full potential professionally and personally. The current challenges and support in workplaces for people living with endometriosis articulates the workplaces' awareness and acknowledgement (or the lack thereof) of the impacts of endometriosis to paid work.

Absenteeism is defined as 'the inability to go to work.'[1] Absenteeism happens when persons suffering from endometriosis 'take leave [paid or unpaid] in order to deal with symptoms.'[2] Presenteeism, on the other hand, is 'going to work because you don't have any more sick leave or being at work at any other time and having a flare in symptoms and then not being as productive as usual…'[3] The evidence provided to the committee from persons suffering from endometriosis shows their experiences of either missing work, being at work but with less capacity to perform their duties, or both.[4]

> It is due to endometriosis that I was unable to complete and put into practice my university degree — an undergraduate bachelor in midwifery — because I was unable to physically manage the shifts and work on my feet due to pelvic, hip, leg/back pain… I am forced to take considerable time off work, and each time I run out of paid leave.[5]

> … with each failed or refused treatment, my peers, co-workers, and employers began to question the validity of my condition, coping skills, and general nature. I started being told to "just muscle through", "just keep working", "be busy to keep your mind off it" as if I hadn't been desperately trying to do this for years already.[6]

Section 2 discussed that both absenteeism and presenteeism are primary cost contributors to a society's public health system and the economy. With absenteeism, the issue of sufficient paid leave comes forth, as often people with endometriosis consume their annual allocated sick and recreational leave for diagnosis, treatment, and management of the condition.[7] In some instances, individuals living with endometriosis lose or quit their jobs.[8] In her presentation to the committee during the hearing in Berri, Ms Turner, shared that since her pain got bad, 'I

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[1] Committee Hansard: Professor Abbot, 11 September 2024, p. 238.
[2] Committee Hansard: Finance Sector Union, 16 October 2024, p. 325.
[3] Committee Hansard: Professor Abbot, 11 September 2024, p. 238.
[4] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Professor Abbott, 11 September 2024; Submissions: 12, 14.
[5] Submission 12, no page numbers.
[6] Submission 14, p. 5.
[7] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Berri hearing (Julie Ahrens, Amara Tuner), 12 June 2024.
[8] See for example Committee Hansard: Berri hearing (Jenny Han), 12 June 2024; Submissions: 2, 20, 83.

have been off work for 22 months now, waiting and trying to get something done to help me with my pain properly.'[9] For some individuals living with endometriosis, questions about their capacity to perform their jobs becomes distressing leading to them quitting their jobs.[10]

> I had explained during this time that I had an impending first procedure to try to diagnose endometriosis and the difficulty and the stress that I had surrounding that because of my sick leave—even though I was still within my entitlements my sick leave was being drained. They were really questioning: 'Do you want to be here? Do you like this job?' that sort of thing. After my first procedure and having to go back into the office a week later and being expected to be there, I chose to leave my job because it was incredibly difficult to get that message across and it was causing me far more stress than I needed to deal with at the time… [11]

In her presentation to the committee, Ms Budai, the National Policy Officer of Finance Sector Union of Australia, elaborated that presenteeism is more disadvantageous to employers because people 'are coming to work, when they are not able to work,' when they could just have not come to work, dealt with endometriosis, and returned to work more capable to perform their responsibilities.[12]

Depending on their employment status and the severity of the symptoms, individuals with endometriosis might earn less or lose their jobs. The evidence provided to the committee indicates that people living with endometriosis experience a compounded financial burden. Currently, the cost of getting adequate and timely diagnosis, treatment, and management for endometriosis is high. It is one of the primary barriers to seeking health advice (Section 9). If an individual receives less salary due to being absent from work, or employed on a casual or part-time basis, it might prevent them from seeking care for endometriosis.[13] Similarly, losing or quitting one's job, places individuals suffering with endometriosis in a more financially challenging position towards paying for endometriosis-related expenses.

In DHAC's presentation to the committee, Ms Schofield, First Assistant Secretary, Cancer, Hearing and Chronic Conditions Division, reports that:

> … the latest data from 2023 from the Australian Longitudinal Study on Women's Health estimates that around one in seven or 14.3 per cent of women born between 1973 and 1978 have been diagnosed with endometriosis by the age of 44 to 49.[14]

Taking into account the average delay in diagnosis, the data provided by DHAC implies that endometriosis related symptoms occur during the peak of a person's educational and working age.[15] For this reason, there is a high probability that endometriosis' negative impact on the work lives of individuals can affect their view of themselves in relation to their abilities to reach

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[9] Committee Hansard: Berri hearing (Amara Turner), 12 June 2024, p. 99.

[10] See for example Committee Hansards: Amy Aikman, 10 July 20204; Finance Sector Union, 16 October 2024.

[11] Committee Hansard: Aikman, 10 July 2024, p. 142.

[12] Committee Hansard: Finance Sector Union, 16 October 2024, p. 325.

[13] See for example Committee Hansard: Berri hearing (Amara Turner), 12 June 2024; Submissions: 12, 14.

[14] Committee Hansard: DHAC (Lisa Schofield), 25 September 2024, p. 306.

[15] Committee Hansard: DHAC (Lisa Schofield), 25 September 2024; Also see Committee Hansard: Professor Abbott, 11 September 2024,

their full potential,[16] including securing a viable future.[17] In her submission, Ms Hudson, outlined gaps in her employment experiences due to having endometriosis, and how she views that she has 'further lost the vital years of establishing and building a career and network needed to ensure viable retirement.'[18] As Kristen Rogers, the Policy and Industrial Services Officer of SA Unions, aptly said,

> We know that work has a profound impact on a person… It is impossible to overstate the influence that work has on people's lives. It's really appropriate to recognise the role that workplaces have, both inside and outside of work for people, and to recognise that there are things in people's lives that can affect their quality of life, and so workplaces have a moral and ethical responsibility to their workers and to our society.[19]

The evidence presented to the committee showed that with proper workplace arrangements and policies, and supportive managers and colleagues, individuals suffering from endometriosis can cope with their conditions.[20] Details of these are presented below.

To summarise, endometriosis affects an individual's ability to work and their productivity through conditions such as absenteeism and presenteeism. Most of the time, the number of leave days are insufficient as endometriosis 'isn't considerate enough to switch itself off between nine to five.'[21] Employees can find themselves in a challenging position if they earn less or lose their jobs, impacting their capacity to pay for treatment and management. Under these circumstances, people suffering from endometriosis feel inadequacy in themselves for not being able to fulfill professional, personal and social goals.

10.2 Work arrangements

The evidence received by the committee outlined the effect of workplace practices and physical set-up on the ability of people with endometriosis to do their duties and sense of self-worth. These workplaces practices are a) reproductive health leave; b) flexible work arrangements; and c) a supportive workplace.

Reproductive health leave and flexible work arrangements

A recent milestone in Australia relative to workplace arrangements is the Queensland Government's Reproductive Health Leave directive that entitles public sector employees to 10 days of reproductive health leave.[22] The directive took effect on 30 September 2024 and can be used by an employee 'when chronic reproductive health conditions (such as, but not limited to, endometriosis, dysmenorrhea, adenomyosis, polycystic ovary syndrome, and menopause

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[16] See for example Committee Hansards: Emma Dempster, 18 September 2024; SA Unions, 13 November 2024.
[17] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Shannon Watkins, 10 July 2024; Submission: 27.
[18] Submission 14, p. 5.
[19] Committee Hansard: SA Unions, 13 November 2024, p. 374.
[20] See for example Committee Hansards: Christie Nancarrow, 19 June 2024; Deanna Flynn Wallis, 19 June 2024; Submissions: 35, 36.
[21] Committee Hansard: SA Unions, 13 November 2024, p. 374.
[22] Queensland Government, *Reproductive Health Leave Frequently Asked Questions*, Office of Industrial Relations, accessed 2 February 2024.

symptoms) require absence from the workplace', among other reproductive health conditions.[23]

In the Queensland Council of Union's presentation to the committee, Ms Mohmood, Industrial Women's Officer, explained that advocating and naming the leave as reproductive health leave rather than menstrual or menopause leave, or endometriosis leave has two benefits. First, it safeguards an employee's privacy regarding their reproductive health as 'our position is that reproductive health should be between an individual and their medical practitioner.'[24] This addresses the concern raised by the committee during the union's presentation relating to the evidence that employees suffering from endometriosis are required to justify the leave.[25]

Second, an encompassing reproductive health leave acknowledges the stigma towards discussing reproductive health issues in the workplace[26] and 'destigmatises' people taking the leave.[27] To some extent, the leave itself conveys the employer's or sector's recognition of the need to take leave when having reproductive health issues[28] or empathy to the worker.[29] This removes the pressure placed upon people with endometriosis 'to break down the social taboo in their context by disclosing that they have a condition such as endometriosis.'[30]

The evidence from the Finance Sector Unions of Australia[31] and SA Unions[32] endorses the Queensland Council of Unions' approach to reproductive health leave. In her presentation to the committee, Ms Budai from the Financial Sector Union of Australia stated that wrapping the leave as reproductive health leave might address the current low uptake of menopause or menstrual leave. Calling it reproductive health leave is more gender inclusive and wider in scope. The only concern that SA Union expressed about the reproductive health leave entitlement within the Queensland's public sector, is it's being mandated through a public sector directive. Ms Clarke, SA Union's Women's Officer, articulated that unless the reproductive health leave entitlement is a legislative reform, rather than a directive, it is at risk of being easily withdrawn.[33]

The finance sector in Australia has made an earlier campaign for a related leave, through the menstrual and menopausal leave. Construction and Building Unions Superannuation Fund,[34] Aware Super, [35] and Future Group [36] are some companies that offer this leave. However, there are questions among private employers, including in the country's major banks, towards

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[23] Queensland Government, *Reproductive Health Leave Frequently Asked Questions*, p. 2.
[24] Committee Hansard: Queensland Council of Unions (Madina Mohmood), 16 October 2024, p. 329.
[25] Committee Hansards: Finance Sector Union, 16 October 2024.
[26] See for example Committee Hansard: Robinson Research Institute, 15 May 2024; Queensland Council of Unions, 16 October 2024; Submission: 41.
[27] Committee Hansard: Queensland Council of Unions (Madina Mohmood),, 16 October 2024, p. 329.
[28] Committee Hansards: Finance Sector Union, 16 October 2024; SA Unions, 13 November 2024.
[29] Committee Hansard: Finance Sector Union, 16 October 2024.
[30] Committee Hansard: Queensland Council of Unions (Madina Mohmood), 16 October 2024, p. 329.
[31] Committee Hansard: Finance Sector Union, 16 October 2024.
[32] Committee Hansard: SA Unions, 13 November 2024.
[33] Committee Hansard: SA Unions, 13 November 2024.
[34] Committee Hansard: Finance Sector Union, 16 October 2024.
[35] S Convery, *Reproductive leave could be a 'gamechanger' for Australian workers – how would it work?*, The Guardian, 2025, accessed 1 February 2025.
[36] Future Group, Future Group's menstrual and menopausal leave policy, Future Group website, 9 January 2024, accessed 1 February 2025.

providing reproductive health leave. Cost to the employer[37] and abuse of the leave,[38] were the identified concerns raised by employers regarding the leave.

Costs to employers have been debunked earlier in the report, as the reproductive health leave is an investment in better employee's health that will 'contribute towards their productivity', eventually leading to 'long-term positive effects' to the employer.[39] A recent study by Bankwest Curtin Economics Centre commissioned by the Health Services Union (including HACSU, Victoria), Aware Super and Queensland Council of Unions found that it would cost the Australian 'economy $26.6 billion a year in lost productivity if workers cannot access 12 days of reproductive health leave. In contrast implementing the said leave for every Australian worker would only cost $920 million'.[40]

As for reproductive health leave being abused by employees, especially women or those AFAB, Mr Tosh, Legislation and Policy Officer at the Queensland Council of Unions, finds it highly unlikely. He stated:

> They (female employees) are either using other forms of leave, which they should be able to use for the purposes for which they are designed, or they are deciding to turn up to work when they probably shouldn't, and that has those impacts (on the workplace).[41]

Ms Mohmood advised for more research, particular empirical evidence, is needed on this topic, especially involving establishments with more female than male employees. Mr Tosh's statement is supported by evidence received by the committee from people living with endometriosis who shared how they deal with the condition relative to performing their jobs.[42]

In terms of updates on this area, the evidence submitted to the committee from selected unions noted that as of 2024, the Australian Council of Trade Unions (ACTU) has endorsed some policy positions in relation to reproductive health and work. One of which is the 'expansion of the National Employment Standards in the federal *Fair Work Act 2009* to provide universal standards for access to 10 days of paid reproductive leave and associated entitlements such as flexible work arrangements and workplace adjustments and accommodations.'[43]

In addition, the report on *Issues related to menopause and perimenopause* by the Parliament of Australia released in September 2024 has recommended for the Commonwealth Government to:

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[37] See for example Committee Hansards: Finance Sector Union, 16 October 2024; Sarah Coshan, 18 September 2024.

[38] See for example Committee Hansard: Finance Sector Union, 16 October 2024, Queensland Council of Unions, 16 October 2024.

[39] Committee Hansard: Queensland Council of Unions (Nate Tosh), 16 October 2024, 29, p. 331.

[40] Health Sector Union (HSU), *Reproductive health taboo costs economy $26 billion a year: New Research*, HSU website, 2025, accessed 1 February 2025.

[41] Committee Hansard: Queensland Council of Unions (Nate Tosh), 16 October 2024, p. 333.

[42] See for example Committee Hansards: Berri hearing (Julie Ahrens), 12 June 2024; Shannon Watkins, 10 July 2024; Amy Aikman, 10 July 2024.

[43] Committee Hansard: SA Unions (Jane Clarke), 13 November 2024, p. 375.

> task the Department of Employment and Workplace Relations to undertake further research on the impact and effectiveness of sexual and reproductive health leave where it has been implemented in Australia and overseas, while giving consideration to introducing paid gender-inclusive reproductive leave in the National Employment Standards (NES) and modern awards.[44]

In the same month, ACTU and Queensland Council of Unions led a delegation of union members and officials to the Commonwealth Government in support of the national reproductive leave campaign. Although 'no commitment' has yet been made[45] to the Queensland Government's action, some progress is expected by unions in the future, given the growing recognition in different workplaces to address the matter of reproductive health leave and putting 'it on the agenda for the Commonwealth parliament to consider.'[46]

Flexible work arrangements are also favourable to individuals living with endometriosis. The unions' presentations to the committee articulate that flexible work arrangements are part of the actions they negotiate in enterprise bargaining. [47] According to Finance Sector Unions of Australia, flexible work arrangements differ by sector and employers.

> … flexibility may be the hours they work, where they are working or the way this work is structured, things like being able to take off your coat when it is really hot or having better uniforms, better provision of menstrual products at work in the bathrooms, so that if someone has an unexpectedly heavy flow, they are not having to deal with the fact of what they are going to do… [48]

The evidence submitted to the committee demonstrates that having flexible work arrangements is helpful to individuals with endometriosis.[49] If an employer offers flexible work arrangements, people living with endometriosis can use flexible work arrangements to manage their condition without using all their annual and sick leave entitlements. Flexible work arrangements are also helpful to those who no longer have leave entitlements. This is the case for Ms Hudson, who outlined in her submission that she accepted the trade-off between the low pay and flexible work arrangements.[50]

> … I didn't want to compromise my position at work, because I really loved my job. It was very stressful and quite a difficult decision for me to leave that position because I loved it so much, but it was just the sheer lack of flexibility.[51]

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[44] Parliament of Australia, *Issues related to menopause and perimenopause* [report], September 2024, accessed 20 October 2024, p. 329; Also see Committee Hansard: Queensland Council of Unions (Madina Mohmood), 16 October 2024, p. 329.

[45] Committee Hansard: SA Unions (Kristen Rogers), 13 November 2024, p. 378.

[46] Committee Hansard: SA Unions (Jane Clarke), 13 November 2024, p. 378.

[47] Committee Hansards: Finance Sector Union, 16 October 202; Queensland Council of Unions, 16 October 2024; SA Unions, 13 November 2024.

[48] Committee Hansard: Finance Sector Union (Angela Budai), 16 October 2024, p. 325.

[49] See for example Committee Hansards: Deanna Flynn Wallis, 19 June 2024; SA Unions, 13 November 2024; Submissions: 27, 35.

[50] Submission 14.

[51] Committee Hansard: Amy Aikman, 1 July 2024, p. 143.

Access to flexible work arrangements helps retain employees.[52] Additionally, this work arrangement acknowledges those individuals who are suffering from endometriosis, but do not necessarily want to take leave.[53]

At the federal level the ACTU and Queensland Council of Unions are advocating via the Queensland Council of Unions' *It's for Everybody Campaign* the introduction of both reproductive health leave entitlements and flexible work arrangements for all Australian workers in the NES.[54]

In summary, providing reproductive health leave and flexible work arrangements are ways to address problems of absenteeism and presenteeism in the workplace for people suffering from endometriosis. In terms of reproductive health leave, the Queensland Government has made progress in this area for the public sector, while some superannuation funds are leading in the private sector. While there are pushbacks from some employers for reasons such as cost and misuse of the leave, these concerns have been disproved. There appears to be less pushback towards flexible work arrangements, but this can vary between employers and sectors. Providing reproductive health leave and flexible work arrangements in workplaces has been brought to the Commonwealth Government's attention.

10.3 Other workplace practices to support persons suffering from endometriosis - supportive leadership team and colleagues and education in workplaces

The evidence made to the committee indicates that having a supportive workplace, including an understanding executive or leadership team, is helpful for people with endometriosis to carry on with their work and look after themselves. Ms McDonald's case is a good composite case of how a supportive and empathetic workplace can assist an employee's performance at work and their self-worth. In her submission, Ms McDonald, who works at the Flight Centre Travel Group, emphasised how the overall supportive environment she has in her company – from managers and colleagues alike - has provided her support and assistance as her health declined due to endometriosis. She further highlights how a supportive leadership team makes a big difference in addressing the taboo and stigma in workplaces toward reproductive health concerns.

> … I also come from a small team of extremely supportive women who back me up and pick up the slack for me at work on many occasions, so I am able to get a little extra rest and maybe come in a bit later or leave earlier when my pain is just so unbearable. Without this team behind me, I would have no choice but to reduce my hours even further to be able to manage my client workload. Since my diagnosis in my current workplace, my manager is incredibly understanding and supportive with my health. Women's health is never particularly easy to be open about, whether talking to the same or opposite gender. I am so thankful for the leadership team at my workplace, who are understanding of this chronic illness…[55]

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[52] See for example Committee Hansard: Berri hearing (Julie Ahrens), 12 June 2024; Submissions: 73, 83.

[53] See for example Committee Hansards: Finance Sector Union, 16 October 2024; Queensland Council of Unions, 16 October 2024; SA Unions, 13 November 2024; Submission: 29, 47.

[54] Committee Hansard: Queensland Council of Unions, 16 October 2024.

[55] Submission 36, no page numbers.

Having understanding managers, team leaders and workmates is essential to the implementation of reproductive health leaves and flexible work arrangements. In SA Union's evidence to the committee, Mr Beasley, Secretary of SA Unions, raised that managers' attitudes and behaviours towards endometriosis influence workers' experiences in getting leave entitlements and support.

> In our written submission we presented three case studies that touched on a lack of understanding by managers, the lack of consistency by managers, and the need for education within workplaces and managerial structures. Worker B and Worker C, both workers with endometriosis, had vastly different experiences and that was primarily due to the managers and the leaders who were in place with responsibility for dictating the workplace culture and determining access to entitlements and support. This was borne out by the AEU's information that a worker's experience will depend on the site leader.[56]

Ms Elston, Board Director of PPFA, has the same position as Mr Beasley. In her presentation, she also outlines how members of the leadership and management team, like herself, who are suffering from endometriosis, can contribute to 'creating a culture of safety' for those individual with endometriosis.

> … I didn't get brave until the last two or three years of my public sector career and then that was in order to set that standard for big branches who reported to me. I thought if I didn't have the courage to say why I was going on four weeks' leave, then how could I expect staff to feel safe and kind of courageous as well? [57]

Relevant to a culture of safety within the workplace, the evidence presented to the committee articulates that information and education sessions on endometriosis in workplaces will prompt or encourage more conversations about the disease.[58] Information and education about reproductive health concerns, including endometriosis, will also help 'protect' the reproductive health entitlements in anti-discrimination and equal opportunity law. In his presentation to the committee, Mr Beasley, from SA Unions, shared that the lack of awareness of this issue in workplaces makes 'women may not feel safe or supported to be able to raise reproductive health issues.'[59] An informed and educated workplace, especially members of the leadership and management will 'dispel the stigma and misunderstandings around endometriosis and reproductive matters.'[60]

PPFA and Endometriosis Australia offer workplace information and education sessions. PPFA indicated that they are keen to conduct PPEP Talk®, in the workplace.[61] The 90-minute program is customised in consideration of the context of the establishment and the needs of employers and employers. PPEP Talk® in the workplace offers practical strategies to improve workplace environments, ensuring that employees experiencing pelvic pain can thrive in their professional roles using 'insightful case studies' that participants can workshop together for

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[56] Committee Hansard: SA Unions (Dale Beasley), 13 November 2024, p. 376.
[57] Committee Hansard: PPFA (MS Danielle Elston), 5 June 2024, p. 58.
[58] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Endometriosis Australia, 30 October 2024; Submissions: 41, 43.
[59] Committee Hansard: SA Unions (Dale Beasley), 13 November 2024, p. 376.
[60] Committee Hansard: SA Unions (Dale Beasley), 13 November 2024, p. 377.
[61] Committee Hansard: PPFA, 5 June 2024; Submission: 43.

learnings.[62] The program also 'delves into the legal obligations of employees and employers, clarifying the rights and responsibilities in managing pelvic pain in the workplace.'[63] In her presentation to the committee, Associate Professor Evans noted that they have just commenced this program as they perceived that many State Government departments in South Australia have issues with absenteeism and/or presenteeism.[64]

Likewise, Endometriosis Australia has launched its EndoAware Program.[65] The program is informed by a national survey that the organisation supported to 'examine the impact of endometriosis on an individual's career and how workplace changes may influence management of endometriosis.'[66]

In her presentation to the committee, Ms Ciccia, Director and Co-founder of Endometriosis Australia, described the EndoAware Program as 'the first evidence-based program in the world for endometriosis in the workplace.'[67] Ms Ciccia stated that the program aims to facilitate the development of informed workplaces that 'benefit both the employee and the employer to retain staff, increase productivity and get the best out of our employees and [the] careers that we choose.'[68]

In conclusion, individuals living with endometriosis strive better in a workplace where members of the leadership and management team as well as colleagues are supportive rather than punitive. How leaders and managers feel and act towards reproductive health issues, including endometriosis, will impact the provision of reproductive health leave and flexible work arrangements. For this reason, the evidence provided to the committee emphasises information and education sessions in workplaces aimed at leadership and management team members. These cohorts are gamechangers to the culture of safety in the workplace relative to reproductive health issues in general, and endometriosis in particular. PPFA's PPEP Talk® in the workplace and Endometriosis Australia's EndoAware Program are examples of programs dealing with endometriosis in the workplace. Like the multidisciplinary care approach in clinically dealing with endometriosis, wraparound supports are helpful in attending to the impact of endometriosis to the work lives of people with the condition.

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[62] Submission 43, no page numbers.
[63] Submission 43, no page numbers.
[64] Committee Hansard: PPFA, 5 June 2024.
[65] Endometriosis Australia, *EndoAware Workplace Accreditation Program,* Endometriosis Australia website, 2024, accessed 25 October 2024.
[66] Endometriosis Australia, *Endometriosis in the Workplace,* 2021, accessed 25 October 2024.
[67] Committee Hansard: Endometriosis Australia, 30 October 2024, p. 360.
[68] Committee Hansard: Endometriosis Australia, 30 October 2024, p. 360.

11. EDUCATION AVAILABLE TO HEALTHCARE PROFESSIONALS, YOUNG WOMEN, AND OTHERS

The necessity of early and on-going education regarding endometriosis cannot be overemphasised. The evidence received by the committee stressed that health and medical professionals, young people, persons living with endometriosis, and their personal and social relations, need to have up-to-date information about the disease as well as diagnostic, treatment and management options.

11.1 Health and medical professionals

Pain is one of the common symptoms associated with endometriosis (though not everyone with endometriosis has pain). For health and medical practitioners to provide appropriate clinical care and management to people with endometriosis, they must have sufficient knowledge and training of chronic pain and endometriosis and its treatment.[1] The evidence submitted to the committee notes that many health and medical professionals have limited knowledge and training in these areas.[2]

Sonographers

Specialist sonographers are needed to detect endometriosis as accurately as possible using TVUSS.[3] As noted in Section 8, gaining expertise in TVUSS depends on the interest and capacity of the sonographer to pursue available continuous professional development courses and supervised hands-on training. The evidence presented to the committee articulates that these factors also explain why upskilling among sonographers is challenging.

The need to upskill sonographers cannot be overemphasised, considering the acknowledgment of imaging, particularly TVUSS, as a diagnostic tool for endometriosis. In her presentation, Ms Deslandes, one of the few expert sonographers in the state, said that one of the reasons for having few specialist sonographers is the lack of mentors in the field.[4] Professor Parange added that there are few imaging centres where sonographers can do practical training in this area and be supervised by expert sonographers. She said that South Australia does not have formal training centres for sonographers, hence, sonographers try to gain practical experience from existing scanning centres. Not all sonographers might be interested and able to pay the associated cost to upskill in this area.[5]

> People (sonographers) upskill… and it's through conferences or having workshops in conferences and things like that. So, people who are interested will go and get trained there, and if… they know somebody in another centre who does these scans, then they can ask, 'Can I come and be an observer?' and if they are willing

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[1] Armour, Mike, et al. Endometriosis and the workplace: Lessons from Australia's response to COVID-19'.

[2] See for example Committee Hansard: PPFA, 5 June 2024; Submission: 10.

[3] See for example Committee Hansards: SHINE Sa, 10 July 2024; YPPPC, 13 November 2024; Submissions: 33, 37, 46, 70.

[4] Committee Hansard: Sonographers, 1 May 2024.

[5] See for example Committee Hansard: Sonographers, 1 May 2024; Submissions: 33, 37.

> to train, that's how it's done. It's already informal; there is no set way of having this kind of process.[6]

One way to facilitate the upskilling of sonographers is to allocate government funding to support sonographers to undertake more training.[7] The evidence received by the committee implies that this kind of support might encourage sonographers to upskill themselves,[8] and not solely be reliant on individual interest and their ability to pay for the education. It is important to realise that upskilling sonographers on performing TVUSS must be done alongside increasing mentors and imaging centres where sonographers can have hands-on experience.

General Practitioners

There is a need for GPs to be adequately educated and trained about endometriosis because of the multiple and complex symptoms of the disease. GPs are also 'gatekeepers' to accessing more specialist care.'[9] Section 8 discusses the reasons why the lack of GP experience and awareness about endometriosis is an obstacle to timely diagnosis, treatment, and management of the condition. It also outlines the challenges if GPs are not equipped with the necessary education and resources to deal with endometriosis.

The evidence received by the committee proposed several areas in which GPs should receive more education and training. These are:

- pelvic health[10] and pain neuroscience;[11]
- non-pelvic/period-specific symptoms of the disease;[12]
- IUD insertion[13]
- advancements in the capacities of the ultrasound and other developments in treatments and managements options;[14] and
- caring for patients as part of a chronic disease management plan.[15]

The evidence received by the committee from the Royal Australian College of General Practitioners (RACGP) indicates that their curriculum and syllabus is supported by resources produced by the organisation, such as *Endometriosis: A review of recent evidence and guidelines*, and the national guidelines, such as the RANZCOG Endometriosis Guideline. The curriculum and syllabus is also embedded with the 'experience of registrar supervisors and medical educators in order to help registrars to implement this guidance within their own clinic and community context.'[16] RACGP's submission noted the availability of 20 endometriosis-specific CDP courses that practising GPs can do through e-learning, face-to-face, and virtual formats. Members of the association also receive a daily publication with articles on various

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[6] Committee Hansard: Sonographers (Professor Nayana Parange), 15 May 2024, p. 30.
[7] See for example Committee Hansard: Sonographers, 1 May 2024; Submissions: 33, 37, 69.
[8] See for example Committee Hansards: Sonographers, 1 May 2024; Submission: 69.
[9] Submission 37, no page numbers.
[10] See for example Submissions: 30, 38, 79.
[11] See for example Committee Hansard: Jane Chalmers, 10 April 2024; Submission: 69.
[12] See for example Submissions: 7, 12, 26, 31, 36, 37, 75, 83.
[13] See for example Submissions: 37, 42, 75, 79.
[14] See for example Committee Hansard: Sonographers, 1 May 2024; Submissions: 24, 33.
[15] See for example Submissions: 42, 54, 75.
[16] Submission 75 additional data.

endometriosis related issues to update them. Moreover, in her submission, Dr Hollington, a chronic pain specialist consultant and Head of Unit of the Central Adelaide Health Network Chronic Pain Management Unit, stated that the Faculty of Pain Medicine offers the online course ‘Better Pain Management’. The course is based on the faculty’s position that ‘early access to education and timely best-practice management’ that considers ‘the whole-person and their context’ would result in better health outcomes and is cost efficient as it lessens unnecessary interventions.[17]

Other than RACGP, PPFA also offers health information sessions for health practitioners. PPFA has a tailored set of educational resources that can upskill and support health practitioners.[18] Like that of the RACGP courses, the PPFA’s Health Professional Education is run via various formats, including ‘bi-monthly online education sessions and online webinars for health and medical practitioners across Australia and New Zealand’.[19] Furthermore, the organisation has an annual RACGP-accredited Health Practitioner Seminar that is ‘super practical so that the things they learn are what they will be able to use on Monday with somebody…’[20]

Within the regional context, initiatives towards the education and training of GPs includes the Yorke Peninsula Pelvic Pain Clinic’s education nights for medical practitioners within the Yorke Peninsula.[21] The submission from South Australia’s Maternal, Neonatal, and Gynaecology Community of Practice (MNGCoP) strategic executive Leadership Committee also mentioned that the Adelaide Endometriosis Research Group, led by Professor Hull ‘have partnered with GP Partners to deliver education for GPs in several regional sites.’[22]

Interstate QENDO’s local community hubs are delivering education and support to increase local health professionals’ capacities in Queensland to deal with individuals living with endometriosis.[23] Based in Tasmania, Vagenius is another online GP-education provider. Vagenius has received various professional associations’ accreditation, including from RACGP and RANZCOG.[24] In addition, the Australian Coalition for Endometriosis has facilitated the delivery of trainings and professional development opportunities for healthcare professionals.[25]

Physiotherapists

Physiotherapy is one of the allied health services required in a multidisciplinary care team. The evidence presented to the committee identifies the need to educate physiotherapists.[26] The submission from Pelvic Floor Health articulated that ‘ongoing education for physiotherapists and other health professionals in the area of endometriosis and pelvic pain is lacking.’[27] Hence, introducing pelvic health at the undergraduate level is important.

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[17] Submission 52, no page numbers.
[18] See Committee Hansard: PPFA, 5 June 2024: Submission 43.
[19] Submission 43.
[20] Committee Hansard: PPFA (Associate Professor Susan Evans), 5 June 2024, p. 64.
[21] Submission 79.
[22] Submission 54, p. 5.
[23] Submissions: 16, 16b.
[24] Committee Hansard: Vagenius Training, 27 November 2024.
[25] Submissions: 17, 17b.
[26] Committee Hansard: Dr Jane Chalmers, 10 April 2024; Submission: 30.
[27] Submission 30, no page numbers.

> While we have data to support physiotherapy as a valuable inclusion in the management plan of patients with endometriosis, ongoing education for physiotherapists and other health professionals in the area of endometriosis and pelvic pain is lacking. We believe that educating physiotherapists at an undergraduate level about the importance of pelvic health physiotherapy for endometriosis patients is essential.[28]

Jane Chalmers, Senior Lecturer in Pain Science at the University of South Australia made the same comment, remarking that 'this is a little-known area of physiotherapy… that is no longer about the tissues in that particularly painful area, [but] more about… a whole body disease... [but] a system-wide… whole body problem when it becomes so chronic.'[29] In addition, the level of detected endometriosis is not correlated with the level of pain that individuals living with endometriosis experience. For this reason, physiotherapists need to specialise in pelvic health to be able to provide adequate and accurate care to individuals living with endometriosis who are experiencing pain.

> All of the women's and pelvic health aspect of our training has been mostly postgraduate. Certainly, when I was an undergraduate there was a little bit of women's health that you could do as an elective, and not all physiotherapy courses offer that. There is not a lot of training out there for the health professionals either…[30]

Other medical practitioners

Apart from nurses (see Section 8), the evidence provided to the committee indicated the need for radiologists to also have knowledge about endometriosis.[31] This would be an essential complementary diagnostic procedure in bolstering the capacity of imaging, especially TVUSS, as a tool to detect endometriosis and guide surgery.[32] In her presentation to the committee, Ms Deslandes mentioned that radiologists might lack confidence in diagnosing endometriosis, especially from TVUSS, without specialised education and training of the condition.[33] She commented, 'If the radiologist reporting the scan doesn't feel confident or doesn't have the skills to recognise that disease process, it can't be reported.'[34]

The evidence presented to the committee also articulates that physicians in emergency departments need education and training to deal endometriosis associated pain.[35] Individuals living with endometriosis, who experience pain, often find themselves in hospital emergency departments.[36] The common feedback is that individuals suffering from endometriosis are not

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[28] Submission 30, no page numbers.

[29] Committee Hansard: Dr Jane Chalmers, 10 April 2024, p. 9.

[30] Committee Hansard: Adelaide Pelvic Pain Network (Jenny Phillips), 10 July 2024, p. 145.

[31] See for example Committee Hansards: Sonography, 1 May 2024; Berri hearing (Jenny Han; Elizabeth Eske), 12 June 2024; Submission: 70.

[32] See for example Committee Hansards: Sonography, 1 May 2024; Berri hearing (Jenny Han), 12 June 2024; Submissions: 70.

[33] Committee Hansard: Sonographers, 1 May 2024.

[34] Committee Hansard: Sonographers (Alison Deslandes), 1 May 2024, p. 21.

[35] See for example Committee Hansards: PPFA, 5 June 2024; Associate Professor George Condous, 10 July 2024.

[36] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; PPFA, 5 June 2024; Rochana Watkins, 10 July 2024; Submissions: 77, 83.

receiving adequate and appropriate care.[37] In her presentation, Associate Professor Evans explained that the response of emergency department doctors is because they are not well-equipped to handle chronic pain.

> I think a major area that is often not recognised is presentations to emergency departments. If you talk to women with pain, they hate going to the emergency departments. Emergency departments are not set up for this thing, so they are not skilled in this area. They dread seeing the pelvic pain patients. The patients dread going to the emergency department…[38]

Finally, the evidence provided to the committee noted that surgeons also need more education regarding pain. In his presentation to the committee, Professor Abbott, the Chair of the National Endometriosis Clinical and Scientific Trials Network and a surgeon, elaborated that surgeons respond to treating and managing chronic pain and/or endometriosis through multiple surgeries. While surgery is necessary for severe cases of endometriosis, Professor Abbott said that 'we need to be a little bit more judicious around our use of surgery.'[39] Acknowledging the power imbalance between patients and surgeons, he emphasised the need to inform surgeons that 'more is not better, particularly where you are not getting a response.'[40]

In conclusion, education, training, and upskilling on endometriosis is necessary across relevant health and medical service providers. GP education is essential to better take patient history and then determine the appropriate test to refer the latter to. Sonographer's need to upskill themselves in order to perform the imaging correctly. For physiotherapists, education and training on pelvic health is essential as endometriosis must be understood from a biopsychosocial perspective. Radiologists, emergency department doctors, and surgeons also require education and updates on dealing with chronic pain and endometriosis based on the roles they play in the diagnosis, treatment, and management of the disease.

11.2 Young people and their personal and social circles

As indicated in Section 9, young people and their families and friends' lack of or limited knowledge and awareness of endometriosis is a barrier to receiving timely and holistic care. The evidence presented to the committee indicates that young people should receive education on endometriosis related topics such as menstruation and period pain early on to assess whether their period pain is normal or not.[41] From this, young people may then make an appointment to see their GP if they feel it is abnormal.[42]

In the evidence received by the committee, PPEP Talk®, the school program of PPFA, is a highly regarded program that provides education on menstruation and endometriosis for

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[37] See for example Committee Hansards: PPFA, 5 June 2024; Berri hearing (Julie Ahrens), 12 June 2024; Rochana Watkins, 10 July 2024; Associate Professor George Condous, 10 July 2024; Submission: 83.

[38] Committee Hansard: PPFA (Associate Professor Susan Evans), 5 June 2024, p. 65.

[39] Committee Hansard: Professor Jason Abbott, 11 September 2024, p. 240.

[40] Committee Hansard: Professor Jason Abbott, 11 September 2024, p. 240.

[41] See for example Committee Hansards: PPFA, 5 June 2024; Associate Professor George Condous, 10 July 2024; Submissions: 5, 7.

[42] Committee Hansard: Robinson Research Institute, 15 May 2024.

young people.[43] PPFA has been delivering the program for over five years to government and non-government secondary school-aged children.[44]

> I am very pleased with the education and tools that they (PPEP Talk®) are giving young women, because then these young women come in knowing what questions to ask, knowing that their period pain is not normal, or they have even been to their other GP and said, 'I would like to go and see that clinic up the road, please. Can you help facilitate a referral for me?' Patients can self-refer, too, but they at least have the tools and the knowledge then to advocate for themselves…[45]

> During my final year as a high school teacher, I had the privilege of participating in the PPEP program, which proved to be transformative for the young people I taught. The boys in my class became more understanding and empathetic towards period pain, and several girls sought support afterwards, having realised through the program that their periods were not normal. It is essential that the PPEP talks be made accessible to all students across the state, including those in remote areas. This knowledge has empowered a new generation of women to seek support earlier in their journey, potentially transforming lives and altering the landscape of women's health for the better.[46]

PPEP Talk® is not a gender-specific education program and is tailor-made based on 'what would work best for the school.'[47] Students who attend the 60-90 minute program learn about:

- pain from the pelvic organs, pain from the pelvic muscles, and pain from the nervous system, to differentiate between common and more complex pain;
- tools to cope with period and pain irregularities, such as using heat, TENS, medications, nutrition, exercise, sleep and stress management;
- the ins and outs of endometriosis, the symptoms and treatments; and
- help seeking strategies to navigate present and future health challenges. [48]

PPEP Talk® is also delivered to sports organisations and to culturally and linguistically diverse communities. The program is customised to 'educate and support athletes, families, coaches, support personnel and clubs about periods and pelvic pain and endometriosis, to ensure that young athletes are not hindered from engaging in sports, but supported.[49] In her presentation to the committee, Ms Connolly, Commissioner for Children and Young People, mentioned that having PPEP Talk® in sports would make a difference in terms of normalising menstruation.[50] Whilst implementing PPEP Talk®, PPFA observed that many students knew little of menstruation and the menstrual cycle. Despite not receiving Commonwealth Government

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[43] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Associate Professor George Condous, 10 July 2024.
[44] Committee Hansard: PPFA, 5 June 2024.
[45] Committee Hansard: YPPPC (Dr Anna Kearney), 13 November 2024, p. 371.
[46] Submission: 83, p. 3
[47] Committee Hansard: PPFA (Michelle Nielsen), 5 June 2024, p. 63.
[48] Submission 43, no page numbers.
[49] Submission 30.
[50] Committee Hansard: Commissioner for Children and Young People, 10 July 2024.

funding, PPFA developed the PPEP Talk® Menstrual Education program. The program is now delivered to students in Grades 5-8 and is Australia's only menstrual education program.[51]

PPEP Talk® was allocated $5 million by the Commonwealth Government for the 2024-25 financial year to continue with its programs.[52] The evidence presented to the committee recommends additional funding for the program as education on menstruation, period pain, and endometriosis can make a difference to young people's live.[53]

A similar initiative is also being worked out by the Commissioner for Children and Young People/Period Justice Working Group. In their presentation, the Period Justice Working Group shared that they have been working with the South Australian Department for Education in amending the curriculum on matters related to health, puberty, and healthy relationships.[54] In this engagement, the group proposed to the Department that menstruation-specific education be separated from sex education and integrated into the broader curriculum. This allows menstrual education to be framed as a factor that contributes to the health literacy of young people. The submission from the Department for Education confirmed this collaboration with the Commissioner for Children and Young People/Period Justice Working Group, as well as other key stakeholders such as the PPFA and academics.[55]

The Commissioner for Children and Young People/Period Justice Working Group also suggested that the delivery of menstrual education should consider the following items, in order to build health literacy of students regarding menstruation:

- age-appropriate information;
- delivered using several information, education, and communication materials and platforms;
- begin with simple messages that can be built-on over time and become more comprehensive as students get older; and
- conveyed in a manner that is not deficit-based.

Furthermore, the evidence provided to the committee suggests that families and peers of young people also need education regarding what constitutes 'normal' menstruation and endometriosis.[56] In her presentation, Ms Nielsen, the National PPEP Talk® manager, noted that for students who perceive that they have unusual period pain and want to provide information to their parents or families, are directed to PPEP Talk® Next Steps sessions. These sessions are free and held once every two months online by Associate Professor Evans. The sessions delve deeper into the topics presented to the students about endometriosis and pelvic pain.[57]

A concern over society's, especially parents', acceptance of a menstrual education subject in schools' curricula was raised. Ms Connolly answered that, with South Australia leading the

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[51] Submission 30.
[52] Commonwealth Government, *Endometriosis Progress Report 2024 Update*, p. 5.
[53] See for example Committee Hansards: PPFA, 5 June 2024; Associate Professor George Condous, 10 July 2024.
[54] Committee Hansard: Commissioner for Children and Young People, 10 July 2024; Also see Submission 39.
[55] Submission 35.
[56] See for example Committee Hansards: Berri hearing (Kaye Schober), 12 June 2024; Associate Professor George Condous, 10 July 2024; Submission: 16-b.
[57] Committee Hansard: PPFA, 5 June 2024.

way, having the subject embedded into the national curriculum, would ascertain that menstrual education is not an ‘optional extra.’[58]

Teachers play an important role in the lives of young people. Nevertheless, in their presentation to the committee, representatives from PPFA reported that in terms of period and pelvic pain and endometriosis, teachers are not comfortable and should not be pressured to teaching these matters. The topics are quite complex, and teachers do not have enough knowledge. Ms Elston said, ‘I would say that if we can't get the baseline for general practice right, it's a really big stretch to expect teachers to have a level of understanding that med students and GPs couldn't produce.’[59] Teachers, however, can teach or reinforce the lessons under a menstrual education subject, if they get upskilled.

> What we are putting forward to the group with the Department for Education here as a potential way of doing that is that there be a face-to-face session in schools that wish to, where we can have an educator go out and do the earlier years menstrual education, really accurately and well … But we can also upskill those teachers so they can be bringing in bits of this to reinforce things.[60]

In summary, providing education on menstruation, period and pelvic pain, and endometriosis to young people and individuals within their personal and social circles, is an important early prevention approach. It is also a ‘cost-effective, life-effective and beneficial thing… to help people early in their pain journey.’[61] PPFA’s PPEP Talk® and the Commissioner for Children and Young People/Period Justice Working Group’s initiatives in this area are making headways towards ensuring that young people’s voices and specific needs are considered in the diagnosis, treatment, and management of endometriosis.

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[58] Committee Hansard: Commissioner for Children and Young People (Helen Connolly), 10 July 2024, p. 146.
[59] Committee Hansard: PPFA (Danielle Elston), 5 June 2024, p. 64.
[60] Committee Hansard: PPFA (Danielle Elston), 5 June 2024, p. 61.
[61] Committee Hansard: PPFA (Associate Professor Evans), 5 June 2024, p. 54.

12. CURRENT RESEARCH AND TRIALS IN AUSTRALIA

The evidence submitted to the committee highlighted current and planned research and trials to facilitate the diagnosis, treatment, and management of the disease. Health economics research and impact studies are also proposed to gauge the implications of current and proposed treatment and management alternatives for people living with endometriosis.

12.1 Diagnosis

The Adelaide Endometriosis Research Group at the Robinson Research Institute has recently developed the EndoZone symptom checker. In their presentation, Dr O'Hara explained that they had not received feedback from GPs regarding the use of the symptom checker by patients. Participants from communities, however, have articulated the modifications they wanted to the platform, and Dr O'Hara is looking forward to assessing the utility of the tool when used in consultations.[1]

In the advent of non-surgical diagnostic tests for endometriosis, the IMAGENDO project at the Robinson Research Institute is prominent in this area.[2] Dr Avery, IMAGENDO Program Manager, described the project as combining 'endometriosis ultrasounds and MRIs digitally to improve the diagnostic sensitivity and specificity and imaging diagnosis in endometriosis.'[3] From this, 'artificial intelligence to interpret ultrasound, and also MRI' is developed and will be used for diagnosis.[4] In addition, the Julia Argyrou Endometriosis Centre at Epworth Healthcare (JAECE) stated in their presentation that they are currently recruiting for an MRI study looking at young people with suspected endometriosis in acknowledgement of complexities when diagnosing young people.[5]

The evidence presented to the committee also mentioned current research on microbiomes. Associate Professor Condous explained in his presentation that the research into the microbiome space is to reinforce the reliability of TVUSS to detect endometriosis. Microbiomes are,

> … microorganisms that live in or on a particular part of the body, such as the skin or gastrointestinal tract. These groups of microorganisms are dynamic and change in response to a host of environmental factors, such as exercise, diet, medication and other exposures.[6]

Associate Professor Condous reported that they have conducted a pilot study and found that, 'albeit in a small number, the microbiome of the oral cavity and the gut was different in those patients with endometriosis.'[7] A larger study on the topic is currently being done to show people suffering from chronic pelvic pain have certain microbial signatures. Contrary to the

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[1] Committee Hansard: Robinson Research Institute, 15 May 2024.
[2] Committee Hansard: Associate Professor George Condous, 10 July 2024; Submission: 37.
[3] Committee Hansard: Robinson Research Institute (Dr Jodie Avery), 15 May 2024, p. 41.
[4] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 145.
[5] Committee Hansard: JAECE (Dr Kate Tyson), 30 October 2024, p. 356.
[6] National Human Genome Research Institute *Microbiome,* 4 February 2025, Microbiome, accessed 5 February 2025.
[7] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 147.

pilot study where they recruited women based on laparoscopy, in a bigger study they are recruiting 300 women and will:

1. Make the diagnosis by ultrasound;
2. Stratify them into either those with low stage or high-stage disease or a completely negative ultrasound scan; and
3. Look at their microbiome signatures using oral swabs.[8]

As noted, research to facilitate and improve the diagnosis of endometriosis includes assessment of usability of online screening tools and trials towards maximising and increasing reliability of imaging tools. A study on individuals' microbial signatures is also underway.

12.2 Treatment and management pathways

As noted in Section 9, Gedeon Richter, the maker of Ryeqo, still needs to lodge with PBAC a required set of documents, after PBAC recommended the hormonal medication in April 2024. Hence, Ryeqo is not currently listed in the PBS.

A hormonal treatment that is in its first phase of human trial is the IUD Alyra.[9] Associate Professor Evans developed the Alyra, a 'very new Mirena coil that also has amitriptyline in it.'[10] The device has progesterone to stop 'lesions from growing and it also diffuses out to the outside of the uterus, so it stops the cycling without stopping ovulation.'[11] Equally important, Alyra also contains 'a pain modifier that modifies that inflammatory response and stops the pain associated at the same time.'[12]

In terms of research on alternative pathways, such as alternative medicines and cannabidiol oil, Associate Professor Condous reported that he and Associate Professor Mike Armour, the Chair of the Australasian Interdisciplinary Researchers in Endometriosis, are doing the study EndoCann. It is a clinical trial on the 'efficacy and safety of two different medicinal cannabis interventions in people with endometriosis and associated pain.'[13] The study will also investigate if these interventions will 'reduce other symptoms of endometriosis, improve quality of life, and effect endometriosis lesion size.'[14]

As shown above, in terms of treatment and management alternatives, clinical trials at different stages are in progress. One is a new hormonal treatment developed in South Australia and the other involves medical cannabis interventions.

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[8] Committee Hansard: Associate Professor George Condous, 10 July 2024, p. 147.

[9] See for example Committee Hansards: Dr Jane Chalmers, 10 April 2024; Robinson Research Institute, 15 May 2024.

[10] Committee Hansard: Robinson Research Institute (Professor Louise Hull), 15 May 2024, p. 37.

[11] Committee Hansard: Robinson Research Institute (Professor Louise Hull), 15 May 2024, p. 41.

[12] Committee Hansard: Robinson Research Institute (Professor Louise Hull), 15 May 2024, p. 41.

[13] Western Sydney University, *EndoCann Study*, NICM Health Research Institute, 2025, accessed 5 February 2025.

[14] Western Sydney University, *EndoCann Study*.

12.3 Economic and/or impact studies

The evidence provided to the committee noted that health economics and cost analyses are required.[15] In her presentation to the committee, Professor Hull emphasised that they have done a superficial health economic analysis for using TVUSS and MRI over surgery and found that the latter is significantly more costly than the imaging tools.[16]

At the national level, the National Endometriosis Clinical and Scientific Trials (NECST) Network continues to bring together 'support for research organisations and conduct clinical trials for endometriosis treatments and services.'[17] Professor Abbott also informed the committee that the project Australian Endometriosis Clinicians Collaborative is ongoing.[18] The project is a 'longitudinal clinical study' that is:

- comparing imaging accuracy of endometriosis in general vs specialised settings;
- comparing medical vs surgical treatment of endometriosis with regards to impact on pain, general health symptoms and quality of life using validate questionnaires; and
- establishing a national biobank of endometriosis for future research capacity. [19]

Professor Abbott reported that one of the key findings from the project is that individuals living with endometriosis 'who do very, very well, they have no symptoms, they have their disease fixed by a medical treatment—sometimes surgery, sometimes other things,'[20] dropout from the study. They would want to conduct a longitudinal study to follow-up on those who dropout of the project 'to know what happens to them over time as well so that we understand the full range of presentation, just like in any other type of chronic disease.'[21]

Furthermore, Professor Abbott mentioned that the Australian Endometriosis Clinicians Collaborative is working with the Centre for Health Economic Research and Evaluation at the University of Technology Sydney to create a quality-of-life questionnaire like the Endometriosis Health Profile with the inclusion of a cost profile. He went on to state that a study on the differential costs in the models of treating and managing endometriosis is on the list of subject matters to be investigated through the Australian Endometriosis Clinicians Collaborative and National Endometriosis Clinical and Scientific Trials Network.

In respect to the cost of reproductive leave, Ms Mohmood from the Queensland Council of Unions informed the committee that they are working together with Curtin University on 'what it would cost for reproductive leave to be included in the NES.'[22] One of the findings of the study is that the 'lack of reproductive leave is costing the Australian economy $26.6 billion a year in lost productivity due to people missing work days, working through pain and sickness and retiring early due to reproductive conditions.'[23] The other finding of the study is that

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[15] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Professor Jason Abbott, 11 September 2024.

[16] Committee Hansard: Robinson Research Institute, 15 May 2024.

[17] University of New South Wales, *Welcome to NECST*.

[18] Committee Hansard: Professor Jason Abbott, 11 September 2024.

[19] Monash University, *The Australian Endometriosis Clinicians Collaborative*, Monash University, 2025, accessed 15 September 2024.

[20] Committee Hansard: Professor Jason Abbott, 11 September 2024, p. 239.

[21] Committee Hansard: Professor Jason Abbott, 11 September 2024, p. 239.

[22] Committee Hansard: Queensland Council of Unions (Madina Mohmood), 16 October 2024, p. 334.

[23] HSU, Reproductive health taboo costs economy $26 billion a year: New research.

‘implementing 12 days of reproductive leave for all Australians would only cost employers $920 million a year, 30 times less than the productivity cost without it.’[24] Thus, providing the reproductive leave through the NES would be more beneficial to Australian society than not providing it.

In general, research on health economics, cost, and impacts of initiatives towards the diagnosis, treatment, and management of endometriosis are currently done to show the worth of these actions in relation to the benefits to the person with the condition and the Australian society.

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[24] HSU, Reproductive health taboo costs economy $26 billion a year: New research.

13. ANY OTHER RELATED MATTERS

The evidence received by the committee raised some topics relevant to the inquiry on endometriosis though not explicitly included in the terms of reference. These topics are: adenomyosis,[1] individuals suffering from endometriosis who are gender or neuro-diverse,[2] and access to superannuation to pay for treatment and management of endometriosis.[3]

Adenomyosis

Adenomyosis is labelled as the 'evil' cousin of endometriosis[4] and less well understood by the general community. The evidence presented to the committee indicated that adenomyosis is a debilitating disease[5] that is often detected in those who have endometriosis[6] and has similar symptoms and impacts.[7] Currently, adenomyosis is treated through a hysterectomy.[8] The evidence provided to the committee indicated that support towards adenomyosis, such as awareness campaigns, funding for services and research, should be increased.[9] Additionally, the evidence received by the committee proposed that adenomyosis be given larger attention in medical schools.[10]

Trans- and gender diverse individuals with endometriosis

The committee also heard evidence concerning trans- or gender-diverse individuals living with endometriosis. SHINE SA implied that these cohorts feel unsafe to seek primary health care services regarding their sexual and reproductive health given the current female-centric model of looking at reproductive health.[11] In a submission made to the committee, an author shared that her daughters, who are suffering from endometriosis and have identified as transgenders, are on a waiting list to see a gynaecologist due to gender dysphoria.[12]

Dr Macrow observed that neurodivergent women are over-represented in the pelvic pain community.[13] The evidence submitted to the committee emphasised that they experience pain differently to others.[14] In her presentation to the committee, Deanna Flynn-Wallis also outlined that 'for those who are in the autism/autistic communities[,] we obviously have heightened sensations, so we experience pain extremely differently from those who aren't autistic.'[15] Dr Macrow explained that this sensory issue for autistic persons, could be due to their nervous,

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[1] See for example Committee Hansards: PPFA, 5 June 2024; Deanna Flynn Wallis, 19 June 2024; Associate Professor George Condous, 10 July 2024; Finance Sector Union Australia, 16 October 2024; Submissions: 64, 70.
[2] See for example Committee Hansards: PPFA, 5 June 2024: Deanna Flynn Wallis, 19 June 2024; Endometriosis Australia, 30 October 2024; Submissions: 79, 83.
[3] See for example Committee Hansards: Berri hearing (Amara Turner), 12 June 2024; DHAC, 25 September 2024; Submissions: 24, 65.
[4] See for example Submissions: 1, 6, 50.
[5] See for example Submissions: 1, 83.
[6] See for example Submissions 70, 71, 83.
[7] See for example Submissions: 70, 83.
[8] See for example Submissions: 6, 36, 50, 70.
[9] See for example Submissions: 6, 70, 83.
[10] See for example Submissions: 70, 83.
[11] Committee Hansard: SHINE SA, 10 July 2024.
[12] Submission 26, no page numbers.
[13] Committee Hansard: Thrive Family Practice (Dr Alecia Macrow), 28 August 2024, p. 234.
[14] Committee Hansards: Deanna Flynn Wallis, 19 June 2024; Thrive Family Practice, 28 August 2024.
[15] Committee Hansard: Deanna Flynn Wallis, 19 June 2024, p. 129.

endocrine, and immune (NEI) systems, where they ‘get a much stronger sensory input from a pain signal than somebody else might.’[16] Hence, a safe and comfortable space in consultation rooms and autism-friendly specialist would be helpful to individuals with endometriosis who are neuro-divergent.

Accessing superannuation to cover medical costs

The committee also heard evidence about accessing superannuation to pay for treatment and management of endometriosis. The evidence outlined that superannuation is being used to pay for surgery in private hospitals and for other private appointments given the long waiting list in public hospitals[17] In her submission to the committee, Ms Elston noted that ‘recent ATO and Treasury analysis found that privately funding endometriosis surgery is one of the top reasons for superannuation withdrawal…’[18] In addition, some people living with endometriosis that are unable to work due to their condition, are accessing income protection insurance. This can be difficult to access, as explained;

> The income protection is offered through our super as nurses, and we pay good money into that to have that service. I don't think that we should then have to wait like we do and fight so hard to get what we are entitled to and what we have paid for… At one stage, it was ten months that I was waiting for the review to be completed.[19]

In summary

People living with endometriosis can have more challenges if they also have adenomyosis or are gender- or neuro-diverse. Getting treatment and management for endometriosis can become highly expensive for people with endometriosis, and some are attempting to access their superannuation and/or income protection insurance to cover some of these costs.

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[16] Committee Hansard: Thrive Family Practice (Dr Alecia Macrow), 28 August 2024, p. 234.

[17] See for example Committee Hansards: Robinson Research Institute, 15 May 2024; Berri hearing (12 June 2024); Submission: 24.

[18] Submission: 24, p. 4

[19] Committee Hansard: Berri hearing (Amara Turner), 12 June 2024, p. 98.

14. CONCLUSION

Endometriosis is a common inflammatory condition affecting girls, women and those AFAB, where endometrial-like tissue grow outside the uterus. Common endometriosis associated symptoms are severe period and pelvic pain, fatigue, and infertility, and its cause and cure are still unknown. However, treatment and management options are available.

In Australia, 1 in 7 of those born between 1973–78 have been diagnosed with endometriosis by age 44–49. There is no official survey on the number of individuals in South Australia who suffer from endometriosis, but the evidence provided to the committee shows similarity to that of the national figures. Endometriosis affects a person's physical and psychological make-up that can impede their education and/or ability to work and impacts their fertility. Seeking diagnosis, treatment, and management for endometriosis is slow and can be financially taxing, affecting peoples" mental and financial capacity.

The NAPE is Australia's blueprint of actions to efficiently and effectively deal with endometriosis. The action plan focuses on initiatives towards clinical management and care, research, and awareness and education to improve health outcomes and reduce the burden of the cost on individuals suffering from endometriosis. Through the NAPE, the RANZCOG's Endometriosis Clinical Practice Guideline was crafted. As part of NAPE's implementation, the Commonwealth Government is also funding the drafting of an endometriosis living guidelines and endometriosis management plan. Another significant document for the diagnosis, treatment, and management of endometriosis is the ESHRE Guidelines for Endometriosis. The Guidelines recently recommended imaging as a useful diagnostic tool for endometriosis, apart from a laparoscopy. This is a significant development towards decreasing the time and expense of diagnosis.

With the endorsement of imaging to diagnose endometriosis, TVUSS and MRI are now considered as diagnostic tools. A tool to raise aware (RATE) and an online screening tool (PIPPA) are available to assist individuals in assessing their symptoms. Endometriosis treatment and management options include analgesics and different hormone therapies. Taking one type of analgesic is usually inadequate to relieve pain so people with endometriosis try different pain relievers. Hormone medicines do not necessarily have the same effect on each person with endometriosis, so they change from one hormonal treatment to another. Some people living with endometriosis also use opiates and have pelvic floor Botox injections.

The different surgeries often performed to treat and manage endometriosis are laparoscopy, hysterectomy, oophorectomy, and endometrial ablation. Repeated surgery, however, does not necessarily result in a better quality of life for the individual. Moreover, individuals suffering from endometriosis also access non-pharmacological and non-surgical means, such as allied health services and natural therapies, to manage their conditions.

The multidisciplinary care model is viewed as the ideal strategy towards treating and managing endometriosis. It is a holistic approach towards the treatment and management of the disease that involves multiple allied health and medical professionals communicating and collaborating with each other. However, there are challenges to achieving the widespread implementation of the multidisciplinary care approach such as location, remuneration of service providers, the number of skilled workforce vis-à-vis the workload. Residing in regional and rural areas makes it challenging to access a multidisciplinary team.

Outside the medical domain, personal relations, advocacy groups and social initiatives play important supportive roles in the management of endometriosis. The support from personal relationships reduces the feeling of isolation among people with endometriosis as they experience the different impact of the disease, and navigate diagnostic, treatment, and management options. Advocacy and social support groups are sources of the latest developments about the disease and related matters. These groups also provide space for insightful exchanges of experiences with other individuals living with endometriosis and experts that validates a person’s experience of the disease as well as providing support and encouragement for people with endometriosis and their families. For these reasons, it is important to support personal and social groups to further contribute to a better quality of life for individuals suffering from endometriosis.

One of the key barriers to the diagnosis, treatment, and management of endometriosis is pain normalisation. Pain is normalised through self-normalisation and the lack of correct and sufficient knowledge about endometriosis for people living with the condition and those around them, including medical practitioners. Normalisation of pain can also happen when medical professionals belittle and dismiss claims of pain and inconvenience by people suffering from endometriosis. Pain normalisation also leads to making the topic on menstruation and endometriosis taboo and creating a stigma towards people with endometriosis.

Another hindrance to the holistic treatment and management of endometriosis is the absence or shortage of health and medical services and providers. The situation is most felt in regional and rural settings, where a constrained workforce contributes to a further lack of multidisciplinary care for individuals in these areas.

Health and medical service providers’ attitudes and behaviours towards people with endometriosis can be an obstacle. Some health and medical practitioners are hesitant to acknowledge patients’ reports of endometriosis related symptoms and/or are insensitive to the patients’ condition. This behaviour makes the latter feel dismissed, rushed during their consultations, and doubtful of themselves and their conditions. The lack of or limited information about endometriosis and current diagnostic tools, treatment, and management options among health and medical service providers contribute to pain normalisation and the lack of empathetic listening and understanding towards people with endometriosis. It is challenging to build a multidisciplinary team if health and medical practitioners have inadequate and outdated knowledge about the disease.

The lack of or limited education or information about menstruation, period and pelvic pain, and endometriosis among young people and their families and friends will hinder adolescents’ timely diagnosis, treatment and management of endometriosis. Educating young people on these matters will help them understand what is normal and not, assist them in managing their condition, while waiting to be seen by a doctor, and help young people advocate for themselves. Having families and friends who are aware and knowledgeable about endometriosis is another facilitating factor to young people’s health-seeking behaviour towards period and pelvic pain and endometriosis.

Endometriosis affects an individual's work through conditions such as absenteeism and presenteeism. While these scenarios negatively impact both employers and employees, the latter is in a more disadvantageous position. If they earn less or lose their jobs, this can affect their capacity to pay for treatment and management. Providing reproductive health leave and flexible work arrangements are ways to address problems on absenteeism and presenteeism in the workplace. Moreover, individuals living with endometriosis strive better in a workplace where members of the leadership and management team as well as colleagues are supportive rather than punitive. How leaders and managers feel and act towards reproductive health issues, including endometriosis, will impact the provision of reproductive health leave and flexible work arrangements.

Education, training, and upskilling on endometriosis is necessary across health and medical service providers, particularly among GPs, sonographers, physiotherapists, radiologists, and emergency department doctors. An essential early response to dealing with endometriosis is education among young people and individuals within their personal and social circles. PPFA's PPEP Talk® and the Commissioner for Children and Young People/Period Justice Working Group's initiatives in this area are making headway towards ensuring that young people's voices and specific needs are considered in the diagnosis, treatment, and management of endometriosis.

Research to facilitate and improve the diagnosis of endometriosis includes assessment of the usefulness of online screening tools and trials towards maximising and increasing reliability of imaging tools. A study on individuals' microbial signatures is also on-going. Clinical trials of treatment and management options are underway. One is a new hormonal treatment developed in South Australia and another involves medical cannabis interventions. Furthermore, research on health economics, cost, and impacts of initiatives regarding the diagnosis, treatment, and management of endometriosis are also in progress.

Overall, the prevalence, severity, and impact of endometriosis on South Australians who have the condition, and South Australia's economic and health systems, and the existing barriers to timely, accurate, and appropriate care, necessitates a comprehensive strategy. This strategy should dismantle social beliefs towards menstruation and associated reproductive health issues, increase education of health and medical practitioners and the public, especially young people, and address the issue of the shortage of health and medical service providers, especially in regional and rural areas. The NAPE and existing guidelines are helpful documents in how the State Government can support the delivery of relevant public health services and professionals, enable and assist initiatives across private and public sectors to contribute to the holistic approach to tackling endometriosis, especially early education, and monitor and regularly assess the performance of these actions.

15. RECOMMENDATIONS AND RATIONALE

The diagnosis, treatment and management of endometriosis is complex, as symptoms can present in different forms and can impact other functions, such as bowel movement, leading to missed diagnosis. The committee has found that endometriosis is best managed through a multidisciplinary care approach.

The key outcome the committee wants this inquiry to achieve is a reduction in the time taken to diagnose endometriosis and for individuals with the conditions to have better health outcomes.

To achieve this, the committee recommends that:

1. **All tertiary training for GPs, gynaecologists, sonographers and allied health professionals place a greater emphasis on the identification and management of endometriosis.**

Rationale: Health and medical professionals need early and substantial training on endometriosis symptoms to ensure timely detection and patients receive the necessary and appropriate care.

2. **SA Health support doctors, nurses, sonographers and allied health practitioners to undertake professional development courses or training in endometriosis and pelvic and period pain diagnosis, treatment and management in order to increase the number of clinicians in the public health sector including emergency departments able to diagnose, treat and manage individuals with endometriosis.**

Rationale: Increasing the current pool of health and medical practitioners in the public sector who are skilled to diagnose, treat and manage endometriosis will ensure more options, timely care and reduced cost spent in going to multiple health and medical service providers. There is a need for more expertise in the public health sector to reduce waiting lists and wait times, as well as provide an affordable option for people without private health insurance.

The evidence presented to the committee articulates that support and remunerations will help increase health and medical practitioners' interest to undertake endometriosis related professional development courses or training. Evidence to the committee suggests cost and time are two factors hindering some medical professionals from undertaking further training in this area.

To measure the effectiveness and efficiency of the support provided, the State Government should assess whether the training is used in daily practice as well as the impact of these initiatives on the number of skilled health and medical providers, the time to diagnosis and the health outcomes of people with endometriosis.

Presentations to emergency departments due to endometriosis related pain needs to be clinically assessed and managed carefully and correctly and referred to an appropriate GP for on-going management.

3. **The State and Commonwealth governments assess existing chronic pain clinics' ability to provide specialist care to endometriosis patients and work together to establish more specialist endometriosis or chronic pain clinics, including public health endometriosis and chronic pain clinics.**

Rationale: Increasing the number of endometriosis and chronic pain clinics will facilitate the timely access to appropriate care. The endometriosis or chronic pain clinics should consist of a multidisciplinary team, ideally led by a GP or nurse coordinator in consultation with a GP, that will provide a multidisciplinary care approach with relevant specialists and allied health professionals and prepare an individualised multidisciplinary care plan. These clinics will further serve as referral and consulting centres where the relevant health and medical practitioners can discuss a patient's medical history, symptoms, possible treatment options and organise a formal referral pathway.

4. **SA Health consider what a best practice model of multidisciplinary care to diagnose, treat and manage endometriosis could be and work with regional service providers, including private practitioners. to utilise face-to-face as well as telehealth to best suit their community.**

Rationale: The evidence provided to the committee implies that there is no single multidisciplinary care or team model. Multidisciplinary care needs to be tailored to individuals based on the location (metropolitan, regional, or remote), available workforce and facilities. However, it is useful to have best practices models for multidisciplinary care and teams that can be redesigned or adjusted based on these factors. Where specialists needed to provide multidisciplinary care are not available in a face-to-face setting, particularly in regional areas, the use of telehealth especially with case conferencing could be utilised.

5. **The Commonwealth and State governments support and incentivise doctors, nurses, sonographers and allied health practitioners with endometriosis training to work in regional, remote, and rural areas, as well as increased access to imaging facilities.**

Rationale: The evidence presented to the committee emphasised the need to provide people residing in regional, remote, and rural areas with greater access to the aforementioned health and medical service providers and imaging facilities to be able to get multidisciplinary care.

6. **SA Health work with RACGP to develop, produce and disseminate endometriosis information kits to GP clinics to give to individuals with endometriosis and others with pelvic pain disease across South Australia.**

Rationale: An endometriosis information pack will help inform and may improve both people with endometriosis, those who may have endometriosis, and the public's knowledge and awareness of endometriosis symptoms, referral pathways, the short- and long-term side effects. It can also advise of the benefits of available diagnosis, treatment and management options, including allied health professions as well as providing links to endometriosis support groups. This information pack can also inform decision-making among individuals who suspect they may have endometriosis, regarding diagnosis, treatment and management pathways. Regional GPs could also work with their Local Health Networks (LHNs) to provide details of local medical professionals and allied health professionals with relevant expertise.

7. **LHNs review how presentations to their emergency departments due to pelvic pain and endometriosis are clinically assessed and managed including the specific number of presentations so that accurate data can be collected.**

Rationale: The committee heard that presentations to emergency departments for people with endometriosis are not specifically recorded leading to no accurate data of how many patients are presenting with endometriosis. Knowing this number will inform SA Health and the Government as to the impact to the public health system, as well as allowing for better resourcing and prioritising of adequate training to allow patients to be referred to endometriosis and chronic pain clinics. Patients will also feel that their concerns are being validated.

8. **State Government work with LHNs and other health advisory organisations to increase the knowledge in the community regarding endometriosis and the availability of specialist services and practitioners in their local area. Through this process, identify gaps in their local areas of allied health/ other medical professionals and work with SA Health to access telehealth to fill these gaps.**

Rationale: LHNs and local health advisory councils (HACs) are important stakeholders in their communities, especially in regional and remote areas. They have the ability to establish a registry of local health and medical practitioners who specialised in the diagnosis, treatment and management of endometriosis and help network these professionals. Further they can facilitate a centralised hub for multidisciplinary care approach to endometriosis and chronic pain management.

LHNs and local HACs can also provide education sessions to the community, as was witnessed by the committee in Berri. This is a mechanism of getting individuals with endometriosis, local interested parties and health and medical professionals together for an information sharing session.

9. **The State Government consider the benefit of establishing a virtual health service for women to reduce barriers and delays in accessing care and support for endometriosis and other women's health issues.**

Rationale: Women are often time poor and cannot access their local GPs when they have a flare-up given the unpredictable nature of symptoms or could be in a regional and remote area. Access to free virtual health care professionals, trained in women's health issues such as endometriosis, will allow quicker access to care, medication and specialist referrals along with referrals for imaging. Free virtual care ensures that there is equality of access to all.

10. **The Commonwealth Government, in conjunction with relevant associations, undertake an education campaign to inform GPs and gynaecologists regarding**

- **available Medicare rebates that allow GPs to refer patients for TVUSS to diagnose endometriosis;**
- **Medicare rebates for gynaecologists to participate in multidisciplinary care teams; and**
- **the updated international and national guidelines that recognise contemporary diagnostic techniques, such as imaging, and contemporary treatment options, such as physiotherapy and nutrition, for individuals with endometriosis.**

Rationale: The evidence received by the committee indicated differences in understanding between GPs and gynaecologists and DHAC of available endometriosis-related MBS items. There is also a gap in knowledge among the aforementioned medical professionals regarding endometriosis international and national guidelines. A comprehensive education campaign can address these gaps in knowledge and understanding.

11. **The Commonwealth Government work with the RACGP and researchers to assess any existing and/or develop an endometriosis symptom checklist and make it available to all GPs to assist them with their patients.**

Rationale: It can be overwhelming for a doctor to know all, if not most, endometriosis related symptoms. A symptom checklist can be useful for individuals and their GPs to assess patient symptoms and facilitate discussion with the patient and possibly other health and medical professionals. The committee heard of RATE, PIPPA, and EndoZone's symptom checker as electronic resources that medical practitioners and their patients can use to identify and assess endometriosis symptoms. Further evaluating these available tools is helpful in promoting its use among patients prior to doctor's appointment or to first time presentation to keep check of their symptoms.

12. **The State Government prepare a broad-base public health campaign regarding endometriosis and other inflammatory pelvic pain symptoms to increase information dissemination to the wider community, and encourage the Local Government Association of South Australia to work with its councils to do the same.**

Rationale: There is a need for information for the wider community regarding endometriosis symptoms and where you can get help. This campaign could include posters with contact details or QR codes that can be included on the back of public toilet doors, in GP surgeries, public notice boards as well as via social media. This will assist in reaching those people not visiting a medical facility or attending school or university, and can include information for non-English speaking members of the community.

13. **The State Government to work with the Commonwealth Government, as a matter of urgency, for Medicare to include a specific item number for endometriosis diagnostic imaging.**

Rationale: A specific MBS item for endometriosis diagnostic imaging is needed to recognise that longer scan times are required for suspected endometriosis cases. Correct and thorough imaging is crucial in informing treatment and management pathways.

14. **The State and Commonwealth governments work together to investigate alternative treatments for endometriosis, such as Botox, and consider its inclusion in the MBS if shown to be an appropriate alternative.**

Rationale: The evidence submitted to the committee notes that Botox can alleviate persistent pelvic pain but is expensive. If rigorous research on the prevalence of pelvic floor Botox use among individuals with endometriosis and the quality of their lives proves Botox as an effective and efficient treatment method, it should be included on MBS.

15. **The Commonwealth Government inquire into the barriers that lead to delays in PBS listings of medicines that can be utilised to manage endometriosis, and ensure that efficient government processing is in place.**

Rationale: Addressing the obstacles causing the delays in the inclusion of new essential medicines for endometriosis on the PBS list, will not only reduce the cost of the disease, but hasten the treatment and management of endometriosis.

16. **The State Government**

- **continue to fund education sessions for students regarding reproductive health, pelvic pain and endometriosis;**
- **ensure these sessions are provided in all public schools where possible and encourage private schools to do the same;**
- **look to expand this funding to include sporting clubs and sessions for parents; and**
- **fund educational campaigns and promotional materials using both mainstream and social media platforms, the back of toilet doors where appropriate, targeted at all public educational institutions (especially secondary and tertiary).**

Rationale: Supporting these initiatives ensures that young people in government schools and tertiary institutions are informed and updated about reproductive health issues, including endometriosis. Young people can then initially assess their conditions and advocate for their treatment. SA schools now have period products available. These could include information about endometriosis, symptom checker packs and other information.

17. **The State Government lobby for the Australian Curriculum to be updated when it is next reviewed, to include improved education content on menstruation, pelvic pain and what is normal and abnormal.**

Rationale: Improving content on these subjects builds young people's health education and literacy over time and lessens the taboo and stigma towards reproductive health issues, including endometriosis, in schools and workplaces. Improvement in the curriculum will also facilitate the employment of a reproductive health expert in schools to handle these courses.

18. **The State Government facilitate a stakeholder forum inviting members of leadership and management teams, from both private and public sectors and unions, to discuss and exchange experiences and ideas in dealing with employees who have reproductive health challenges, including endometriosis.**

Rationale: Having this forum will inform both private and public sectors of best practices in dealing with employees with reproductive health challenges, including endometriosis. Moreover, it will help the State Government determine support mechanisms for both public and private sectors to create or maintain supportive workplaces.

19. **The State Government assess current flexible work arrangements available to public sector employees to ensure they are providing staff with the flexibility they need when they are managing their serious pelvic pain, and consider the introduction of reproductive health leave, in addition to sick leave, for people with chronic reproductive health issues.**

Rationale: In the Queensland public sector, some employers within the finance sector and several private organisations have introduced reproductive leave, which research has shown to improve productivity and morale of staff. Conducting research on and cost-benefit analyses for different workplace arrangements in South Australian public sector will inform the decision on how flexible work arrangements can be further adopted and improved and how reproductive health leave could be best implemented, either through a directive (such as the Queensland Government) or legislation reform.

20. **The Commonwealth Government increase and prioritise funding and support for women's reproductive health research as well as clinical trials involving girls, women, and those AFAB, especially on health matters that are commonly or exclusively experienced by these cohorts, including endometriosis.**

Rationale: The committee heard that SA is leading the way in endometriosis research, but there is currently limited grant funding for this research. Large and systematic research, especially those conducted and led by women researchers, on the reproductive health of girls, women and those AFAB should be given priority for funding allocation and grants to ascertain that these cohorts are not overlooked in terms of access to timely, appropriate, and holistic health care and developments in this area. The Commonwealth Government should also ensure that results from research are translated into practice, such as clinical practices and professional guidelines.

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17. APPENDIX

17.1 Submissions received

Submission number	Name	Date received by Committee
1	Anonymous	10 April 2024
2	Nicoli Ackland	10 April 2024
3	Anonymous	10 April 2024
4	Adelaide Hills O & G	1 May 2024
5	Australian Coalition for Endometriosis	1 May 2024
6	Michelle Roberts	1 May 2024
7	Vanessa	1 May 2024
8	Anonymous	15 May 2024
9	Anonymous	15 May 2024
10	Dr Joy Ohazy	15 May 2024
11	Yorke Peninsula Pelvic Pain Clinic, Kadina	15 May 2024
12	Joelie Croser	15 May 2024
13	Confidential	15 May 2024
14	Sophia Hudson	15 May 2024
15	Confidential	15 May 2024
16	QENDO	5 June 2024
17	ACE	5 June 2024
18	Kellie Jordan	5 June 2024
19	Sevastine Contouris	5 June 2024
20	Ellis Sandhu	5 June 2024
21	Nicala Roden	5 June 2024
22	Dr Leyla Moghaddasi	5 June 2024
23	Hannah Pfitzner	5 June 2024
24	Danielle Elston	5 June 2024
25 Part 1 & 2	Thrive Family Practice	5 June 2024
26	Anonymous	5 June 2024
27	Ellen O’Dea	5 June 2024
28	City of Onkaparinga Women’s Group	5 June 2024
29	Anonymous	5 June 2024
30	Pelvic Floor Health	5 June 2024
31	Sylvia Hrehoresen	5 June 2024
32	Vicky Lamonby	5 June 2024
33	Australasian Sonographers Association	5 June 2024
34	Robinson Research Institute (Prof Louise Hull, Dr Jodie Avery, Dr Beck O’Hara)	5 June 2024
35	Department for Education	5 June 2024
36	Anonymous	5 June 2024
37	Robinson Research Institute (Dr Abeygunasekara, A/Prof Gonzalez-Chica, Prof Louise Hull, Dr Jodie Avery, Dr Beck O’Hara	5 June 2024
38	Adelaide Pelvic Pain	5 June 2024

Submission number	Name	Date received by Committee
39	Commissioner for Children and Young People - Peoples Period Justice Working Group	5 June 2024
40	Anonymous	5 June 2024
41	Finance Sector Union of Australia	5 June 2024
42	Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)	5 June 2024
43	Pelvic Pain Foundation	5 June 2024
44	Rochana Watkins	5 June 2024
45	Confidential	5 June 2024
46	Endometriosis Australia	5 June 2024
47	Anonymous	5 June 2024
48	Confidential	5 June 2024
49	Confidential	5 June 2024
50	Lynette / Anonymous	5 June 2024
51	NM / Anonymous	5 June 2024
52	Dr Irina Hollington	5 June 2024
53	Jean Hailes	5 June 2024
54	SA Health Maternal Neonatal & Gynaecology Strategic Executive Leadership Committee	5 June 2024
55	McKell Institute	5 June 2024
56	Anonymous	5 June 2024
57	Australian Medical Association	5 June 2024
58	Jessica Hoppo	5 June 2024
59	Hayley Duff	5 June 2024
60	Megan Hand	5 June 2024
61	Kelsi Dodds	5 June 2024
62	Tracy Mason	5 June 2024
63	Kristy Fairlamb	5 June 2024
64	Queensland Council of Unions	5 June 2024
65	Greens SA Members of Parliament	5 June 2024
66	Minister for Women and the Prevention of Domestic, Family and Sexual Violence	5 June 2024
67	Gedeon Richter	5 June 2024
68	Dr Alex Liew	5 June 2024
69	Australasian Interdisciplinary Researchers in Endometriosis (AIRE)	5 June 2024
70	Anonymous	5 June 2024
71	Molly McCarthy	5 June 2024
72	Libby Trainor Parker	5 June 2024
73	SA Unions	19 June 2024
74	Stacey Wurfel	19 June 2024
75	Royal Australian College of General Practitioners (RACGP)	19 June 2024
76	Anonymous	19 June 2024
77	Anonymous	10 July 2024
78	Anonymous	10 July 2024
79	SHINE SA	10 July 2024

Submission number	Name	Date received by Committee
80	Felicity Hampel	10 July 2024
81	Judy McKay	28 August 2024
82	Confidential	28 August 2024
83	Joanne Scott	28 August 2024
84	Confidential	25 September 2024
85	Dr Diana Cross	25 September 2024

17.2 Hearings

The Committee held the majority of its hearings in Old Parliament House in Adelaide, hearing from witnesses in person and via MS Teams. It also undertook two regional trips, to Berri in the Riverland and Mount Gambier to hear from witnesses in these regional centres. The Riverland hearing was held at the Berri Hotel and the Mount Gambier hearing was held at the Commodore Hotel.

All witnesses were heard in public, between April and November 2024.

Date	Witnesses	Location
10 April	Dr Jane Chalmers Senior Lecturer in Pain Science at UniSA	Adelaide
1 May	Professor Nayana Parange - Professor of Medical Sonography and Professional Lead, Allied Health and Human Performance – UniSA Ms Alison Deslandes - Specialist Gynaecologist Sonographer and University of Adelaide Researcher Ms Shae Maple - Specialist Sonographer and UniSA Researcher	Adelaide
15 May	***Robinsons Research Institute, University of Adelaide*** Prof Louise Hull - Head of Adelaie Endometriosis Group, Robinson Research Institute; and Principal Investigator, IMAGEndo Dr Jodie Avery - Senior Research Fellow, Adelaide Medical School, Robinsons Research Institute; and Program Manager/Chief Investigator, IMAGEndo Dr Rebecca O’Hara - Chief Investigator, IMAGEndo	Adelaide
5 June	***Pelvic Pain Foundation of Australia*** Assoc Prof Susan Evans - Executive Chair Ms Danielle Elston - Board Director Ms Michelle Nielsen (via Teams) - National PPEP Talk Manager	MS Teams
12 June	Dr Nasser Shehata - Consultant Gynaecologist and Obstetrician, Riverland General Hospital	Berri
12 June	Ms Julie Ahrens	Berri
12 June	Ms Kaye Schober	Berri
12 June	Ms Jenny Han	Berri
12 June	Ms Amara Turner	Berri
12 June	Ms Jesse Lang	Berri
12 June	Ms Elizabeth Eske – Physiotherapist, **Physio Women’s and Pelvic Health Physio**	Berri

Date	**Witnesses**	**Location**
19 June	Ms Christie Nancarrow	MS Teams
19 June	Ms Deanna Flynn Wallis	Adelaide
10 July	***Adelaide Pelvic Pain Network*** Ms Sonia Scharfbillig - APA Titled Continence and Women's Health Physiotherapist Dr Carmel Reynolds – General Practitioner Ms Jenny Phillips - APA Titled Continence and Women's Health Physiotherapist and Acting Head of Unit, Women's Health Physiotherapy, WCH Ms Amanda Gierasch - Adelaide Health Psychology	Adelaide
10 July	Associate Professor George Condous - Associate Professor of Gynaecology, University of Sydney; Head of Gynaecology, Nepean Hospital, Sydney; and Director of OMNI Ultrasound and Sydney Endometriosis	Adelaide
10 July	Ms Rochana Watkins Mr Shannon Watkins	Adelaide
10 July	Ms Amy Aikman	Adelaide
10 July	Ms Georgia Gosse	Adelaide
10 July	***Commissioner for Children and Young People*** Ms Helen Connolly - Commissioner for Children and Young People Ms Valeria Caceres Galvez - Period Justice Working Group Ms Loryn Cody - Period Justice Working Group Ms Sithuki Seelaman - Period Justice Working Group	Adelaide
10 July	***SHINE SA*** Dr Clare Keogh - General Practitioner Ms Jessica Willis - Director Clinical and Counselling Services Division	Adelaide
10 July	***Royal Australian and New Zealand College of Obstetricians and Gynaecologists*** Dr Heather Waterfall – Chair, South Australian State and Northern Territory Committee, Royal Australian and New Zealand College of Obstetricians and Gynaecologists Dr Magda Halt, Gynaecologist, RANZCOG Councillor for SA, Member South Australian State and Northern Territory Committee, Royal Australian and New Zealand College of Obstetricians and Gynaecologists	Adelaide
28 August	***Thrive Family Practice (Thrive Endo Clinic)*** Dr Alecia Macrow, GP and Director Mrs Cherie Noble, Exercise Physiologist	Adelaide
11 September	Professor Jason Abbott Chair, National Endometriosis Clinical and Scientific Trials (NECST) Network	Adelaide
11 September	Dr Alex Liew	Adelaide
18 September	Ms Sarah Coshan, Pelvic Health Physiotherapist - **Embody Women's Health**	Mount Gambier
18 September	**Hawkins Medical Clinic** Dr Monique Kanters - GP	Mount Gambier
18 September	Ms Lucy Savage Year 12 student, St Martins Lutheran College	Mount Gambier

Date	Witnesses	Location
18 September	Ms Eloise Zanoni, Physiotherapist - **iCAN Physiotherapy**	Mount Gambier
18 September	Ms Lucy Lines, Embryologist and Fertility Educator - **Two Lines Fertility**	Mount Gambier
18 September	Ms Gayelene Allen	Mount Gambier
18 September	Ms Emma Dempster, Exercise Physiologist - **Proactive Health**	Mount Gambier
18 September	Ms Stacey Seedon	Mount Gambier
25 September	**Australian Government Department of Health and Aged Care** Ms Lisa Schofield, First Assistant Secretary, Cancer, Hearing and Chronic Condition Division Mr Steve Dunlop, Director, Medicare Benefits and Digital Health Division Ms Imogen Colton, Director, Medicare Benefits and Digital Health Division Dr Rebecca Jacobs, Medical Officer, Medicare Benefits and Digital Health Division Ms Polly Logmans, Assistant Director, Medicare Benefits and Digital Health Division Ms Vanessa McMahon, Director, Technology Assessment and Access Division Mr Chris Carlile, Assistant Secretary, Cancer, Hearing and Chronic Condition Division Dr Vanessa Burgess, Director, Cancer, Hearing and Chronic Condition Division	MS Teams
16 October	***Finance Sector Union of Australia*** Ms Angela Budai, National Policy Officer Mr Nikhil Singh, Campaign Manager	MS Teams
16 October	***Queensland Council of Unions*** Ms Madina Mohmood, Industrial Women's Officer Mr Nate Tosh, Legislative and Policy Officer	MS Teams
21 October	Dr Colin Weatherill, Head of Unit, Obstetrics and Gynaecology - Mount Gambier Hospital	Adelaide
30 October	***Julia Argyrou Endometriosis Centre at Epworth Healthcare*** Ms Nikki Campbell, Endometriosis Nurse Coordinator Dr Kate Tyson, Centre Director	MS Teams
30 October	***Endometriosis Australia*** Ms Donna Ciccia, Director and Co-Founder	MS Teams
13 November	***Yorke Peninsula Pelvic Pain Clinic*** Dr Anna Kearney Dr Eleanor Daniel	MS Teams
13 November	***SA Unions*** Mr Dale Beasley, Secretary Ms Kristen Rogers, Policy and Industrial Services Coordinator Ms Jane Clarke, Women's Officer	Adelaide
27 November	**Vagenius Training** Ms Colette McKiernan, Co-Founder and Trainer and Educator	MS Teams

Date	Witnesses	Location
	Ms Rachel Andrew, Co-Founder and APA Continence and Women’s Health Physiotherapist Dr Emily Ware, Women’s Health GP Specialist	

17.3 MBS questions on notice response

MBS items that may be billed for patients who have endometriosis
MBS Fee and full item descriptors including time requirements where applicable

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
23	$42.85	Professional attendance by a general practitioner at consulting rooms (other than a service to which another item in this Schedule applies), lasting at least 6 minutes and less than 20 minutes and including any of the following that are clinically relevant:(a) taking a patient history;(b) performing a clinical examination;(c) arranging any necessary investigation;(d) implementing a management plan;(e) providing appropriate preventive health care;for one or more health-related issues, with appropriate documentation
36	$82.90	Professional attendance by a general practitioner at consulting rooms (other than a service to which another item in the table applies), lasting at least 20 minutes and including any of the following that are clinically relevant: (a) taking a detailed patient history; (b) performing a clinical examination; (c) arranging any necessary investigation; (d) implementing a management plan; (e) providing appropriate preventive health care; for one or more health-related issues, with appropriate documentation-each attendance
44	$122.15	Professional attendance by a general practitioner at consulting rooms (other than a service to which another item in the table applies), lasting at least 40 minutes and including any of the following that are clinically relevant: (a) taking an extensive patient history; (b) performing a clinical examination; (c) arranging any necessary investigation; (d) implementing a management plan; (e) providing appropriate preventive health care; for one or more health-related issues, with appropriate documentation-each attendance
53	$21.00	Professional attendance at consulting rooms of more than 5 minutes in duration but not more than 25 minutes (other than a service to which any other item applies)-each attendance, by: (a) a medical practitioner (who is not a general practitioner); or (b) a Group A1 disqualified general practitioner, as defined in the dictionary of the General Medical Services Table (GMST).
54	$38.00	Professional attendance at consulting rooms of more than 25 minutes in duration but not more than 45 minutes (other than a service to which any other item applies)-each attendance, by: (a) a medical practitioner (who is not a general practitioner); or (b) a Group A1 disqualified general practitioner, as defined in the dictionary of the General Medical Services Table (GMST).
57	$61.00	Professional attendance at consulting rooms lasting more than 45 minutes, but not more than 60 minutes (other than a service to which any other item applies) by:(a) a medical practitioner who is not a general practitioner; or(b) a Group A1 disqualified general practitioner

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
104	$98.95	Professional attendance at consulting rooms or hospital by a specialist in the practice of the specialist's specialty after referral of the patient to the specialist-each attendance, other than a second or subsequent attendance, in a single course of treatment, other than a service to which item 106, 109 or 16401 applies
105	$49.75	Professional attendance by a specialist in the practice of the specialist's specialty following referral of the patient to the specialist-an attendance after the first in a single course of treatment, if that attendance is at consulting rooms or hospital, other than a service to which item 16404 applies
110	$174.50	Professional attendance at consulting rooms or hospital, by a consultant physician in the practice of the consultant physician's specialty (other than psychiatry) following referral of the patient to the consultant physician by a referring practitioner-initial attendance in a single course of treatment
116	$87.30	Professional attendance at consulting rooms or hospital, by a consultant physician in the practice of the consultant physician's specialty (other than psychiatry) following referral of the patient to the consultant physician by a referring practitioner-each attendance (other than a service to which item 119 applies) after the first in a single course of treatment
123	$197.90	Professional attendance by a general practitioner at consulting rooms (other than a service to which another item in this Schedule applies), lasting at least 60 minutes and including any of the following that are clinically relevant:(a) taking an extensive patient history;(b) performing a clinical examination;(c) arranging any necessary investigation;(d) implementing a management plan;(e) providing appropriate preventive health care;for one or more health related issues, with appropriate documentation
132	$305.15	Professional attendance by a consultant physician in the practice of the consultant physician's specialty (other than psychiatry) of at least 45 minutes in duration for an initial assessment of a patient with at least 2 morbidities (which may include complex congenital, developmental and behavioural disorders) following referral of the patient to the consultant physician by a referring practitioner, if: (a) an assessment is undertaken that covers: (i) a comprehensive history, including psychosocial history and medication review; and (ii) comprehensive multi or detailed single organ system assessment; and (iii) the formulation of differential diagnoses; and (b) a consultant physician treatment and management plan of significant complexity is prepared and provided to the referring practitioner, which involves: (i) an opinion on diagnosis and risk assessment; and (ii) treatment options and decisions; and (iii) medication recommendations; and (c) an attendance on the patient to which item 110, 116 or 119 applies did not take place on the same day by the same consultant physician; and (d) this item has not applied to an attendance on the patient in the preceding 12 months by the same consultant physician

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
133	$152.80	Professional attendance by a consultant physician in the practice of the consultant physician's specialty (other than psychiatry) of at least 20 minutes in duration after the first attendance in a single course of treatment for a review of a patient with at least 2 morbidities (which may include complex congenital, developmental and behavioural disorders) if: (a) a review is undertaken that covers: (i) review of initial presenting problems and results of diagnostic investigations; and (ii) review of responses to treatment and medication plans initiated at time of initial consultation; and (iii) comprehensive multi or detailed single organ system assessment; and (iv) review of original and differential diagnoses; and (b) the modified consultant physician treatment and management plan is provided to the referring practitioner, which involves, if appropriate: (i) a revised opinion on the diagnosis and risk assessment; and (ii) treatment options and decisions; and (iii) revised medication recommendations; and (c) an attendance on the patient to which item 110, 116 or 119 applies did not take place on the same day by the same consultant physician; and (d) item 132 applied to an attendance claimed in the preceding 12 months; and (e) the attendance under this item is claimed by the same consultant physician who claimed item 132 or a locum tenens; and (f) this item has not applied more than twice in any 12 month period
721	$164.35	Attendance by a general practitioner for preparation of a GP management plan for a patient (other than a service associated with a service to which any of items 735 to 758 apply)
723	$130.25	Attendance by a general practitioner to coordinate the development of team care arrangements for a patient (other than a service associated with a service to which any of items 735 to 758 apply)
735	$80.55	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to organise and coordinate: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 15 minutes, but for less than 20 minutes (other than a service associated with a service to which items 721 to 732 apply)
739	$137.75	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to organise and coordinate: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 20 minutes, but for less than 40 minutes (other than a service associated with a service to which items 721 to 732 apply)
743	$229.65	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to organise and coordinate: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 40 minutes (other than a service associated with a service to which items 721 to 732 apply)
747	$59.20	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 15 minutes, but for less than 20 minutes (other than a service associated with a service to which items 721 to 732 apply)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
750	$101.45	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 20 minutes, but for less than 40 minutes (other than a service associated with a service to which items 721 to 732 apply)
758	$168.80	Attendance by a general practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; or (c) a multidisciplinary discharge case conference; if the conference lasts for at least 40 minutes (other than a service associated with a service to which items 721 to 732 apply)
820	$160.80	Attendance by a consultant physician in the practice of the consultant physician's specialty, as a member of a case conference team, to organise and coordinate a community case conference of at least 15 minutes but less than 30 minutes, with a multidisciplinary team of at least 3 other formal care providers of different disciplines
822	$241.35	Attendance by a consultant physician in the practice of the consultant physician's specialty, as a member of a case conference team, to organise and coordinate a community case conference of at least 30 minutes but less than 45 minutes, with a multidisciplinary team of at least 3 other formal care providers of different disciplines
823	$321.55	Attendance by a consultant physician in the practice of the consultant physician's specialty, as a member of a case conference team, to organise and coordinate a community case conference of at least 45 minutes, with a multidisciplinary team of at least 3 other formal care providers of different disciplines
825	$115.50	Attendance by a consultant physician in the practice of the consultant physician's specialty, as a member of a multidisciplinary case conference team of at least 2 other formal care providers of different disciplines, to participate in a community case conference (other than to organise and coordinate the conference) of at least 15 minutes but less than 30 minutes, with the multidisciplinary case conference team
826	$184.25	Attendance by a consultant physician in the practice of the consultant physician's specialty, as a member of a multidisciplinary case conference team of at least 2 other formal care providers of different disciplines, to participate in a community case conference (other than to organise and coordinate the conference) of at least 30 minutes but less than 45 minutes, with the multidisciplinary case conference team
2801	$174.50	Professional attendance at consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-initial attendance in a single course of treatment
2806	$87.30	Professional attendance at consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-each attendance (other than a service to which item 2814 applies) after the first in a single course of treatment

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
2814	$49.75	Professional attendance at consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-each minor attendance after the first attendance in a single course of treatment
2824	$211.65	Professional attendance at a place other than consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-initial attendance in a single course of treatment
2832	$128.05	Professional attendance at a place other than consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-each attendance (other than a service to which item 2840 applies) after the first in a single course of treatment
2840	$92.25	Professional attendance at a place other than consulting rooms or hospital by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine following referral of the patient to the specialist or consultant physician by a referring practitioner-each minor attendance after the first attendance in a single course of treatment
2946	$160.80	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a community case conference of at least 15 minutes but less than 30 minutes
2949	$241.35	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a community case conference of at least 30 minutes but less than 45 minutes
2954	$321.55	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a community case conference of at least 45 minutes
2958	$115.50	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a community case conference (other than to organise and coordinate the conference) of at least 15 minutes but less than 30 minutes
2972	$184.25	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a community case conference (other than to organise and coordinate the conference) of at least 30 minutes but less than 45 minutes
2974	$252.95	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a community case conference (other than to organise and coordinate the conference) of at least 45 minutes

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
2978	$160.80	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a discharge case conference of at least 15 minutes but less than 30 minutes, before the patient is discharged from a hospital (H)
2984	$241.35	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a discharge case conference of at least 30 minutes but less than 45 minutes, before the patient is discharged from a hospital (H)
2988	$321.55	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to organise and coordinate a discharge case conference of at least 45 minutes, before the patient is discharged from a hospital (H)
2992	$115.50	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a discharge case conference (other than to organise and coordinate the conference) of at least 15 minutes but less than 30 minutes, before the patient is discharged from a hospital (H)
2996	$184.25	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a discharge case conference (other than to organise and coordinate the conference) of at least 30 minutes but less than 45 minutes, before the patient is discharged from a hospital (H)
3000	$252.95	Attendance by a specialist, or consultant physician, in the practice of the specialist's or consultant physician's specialty of pain medicine, as a member of a multidisciplinary case conference team, to participate in a discharge case conference (other than to organise and coordinate the conference) of at least 45 minutes, before the patient is discharged from a hospital (H)
91801	$82.90	Telehealth attendance by a general practitioner lasting at least 20 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a detailed patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care. NOTE: It is a legislative requirement that this service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91802	$122.15	Telehealth attendance by a general practitioner lasting at least 40 minutes if the attendance includes any of the following that are clinically relevant: (a) taking an extensive patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care. NOTE: It is a legislative requirement that this service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91803	$21.00	Telehealth attendance by a medical practitioner of more than 5 minutes in duration but not more than 25 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a short patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care. NOTE: It is a legislative requirement thatthis service must be

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
		performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91804	$38.00	Telehealth attendance by a medical practitioner of more than 25 minutes in duration but not more than 45 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a detailed patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care; NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91805	$61.00	Telehealth attendance by a medical practitioner (not including a general practitioner) of more than 45 minutes in duration but not more than 60 minutes if the attendance includes any of the following that are clinically relevant: (a) taking an extensive patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care NOTE: It is a legislative requirement that this service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91806	$34.25	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), in an eligible area, of more than 5 minutes in duration but not more than 25 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a short patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91807	$66.35	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), in an eligible area, of more than 25 minutes in duration but not more than 45 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a detailed patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91808	$97.70	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), in an eligible area, of more than 45 minutes in duration but not more than 60 minutes if the attendance includes any of the following that are clinically relevant: (a) taking an extensive patient history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventative health care NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
91833	$49.75	Phone attendance for a person by a specialist in the practice of the specialist’s specialty if: (a) the attendance follows referral of the patient to the specialist; and (b) the attendance was of more than 5 minutes in duration. Where the attendance is after the first attendance as part of a single course of treatment.

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
92004	$241.85	Telehealth attendance by a general practitioner for a health assessment of a patient - this item or items 93470 or 93479 not more than once in a 9 month period. NOTE: It is a legislative requirement that this service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for the definition of 'patient's usual medical practitioner' as some exemptions do apply).
92025	$130.25	Telehealth attendance by a general practitioner, to coordinate the development of team care arrangements for a patient (other than a service associated with a service to which any of items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It is a legislative requirement thatthis service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for thedefinition of 'patient's usual medical practitioner' as some exemptions do apply).
92026	$80.20	Contribution by a general practitioner by telehealth, to a multidisciplinary care plan prepared by another provider or a review of a multidisciplinary care plan prepared by another provider (other than a service associated with a service to which any of items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It is a legislative requirement thatthis service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for thedefinition of 'patient's usual medical practitioner' as some exemptions do apply).
92028	$82.10	Telehealth attendance by a general practitioner to review or coordinate a review of:(a) a GP management plan prepared by a general practitioner (or an associated general practitioner) to which items 229 or 721 of the general medical services table, or item 92024, 92055, 92068 or 92099 applies;(b) team care arrangements which have been coordinated by the general practitioner (or an associated general practitioner) to which items 230 or 723 of the general medical services table, or item 92025 or 92069 applies NOTE: It is a legislative requirement thatthis service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for the definition of 'patient's usual medical practitioner' as some exemptions do apply).
92055	$131.50	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), for preparation of a GP management plan for a patient (other than a service associated with a service to which any of items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It is a legislative requirement thatthis service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for the definition of 'patient's usual medical practitioner' as some exemptions do apply).
92056	$104.20	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), to coordinate the development of team care arrangements for a patient (other than a service associated with a service to which any of items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It is a legislative requirement thatthis service must be performed by the patient's usual medical practitioner (please see Note AN.1.1 for the definition of 'patient's usual medical practitioner' as some exemptions do apply).
92057	$64.15	Contribution by a medical practitioner (not including a general practitioner, specialist or consultant physician) by telehealth to a multidisciplinary care plan prepared by another provider or a review of a multidisciplinary care plan prepared by another provider (other than a service associated with a service to which any of items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
		is a legislative requirement that this service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
92058	$64.15	Contribution by a medical practitioner (not including a general practitioner, specialist or consultant physician) by telehealth to:(a) a multidisciplinary care plan for a patient in a residential aged care facility, prepared by that facility, or to a review of such a plan prepared by such a facility; or(b) a multidisciplinary care plan prepared for a patient by another provider before the patient is discharged from a hospital, or to a review of such a plan prepared by another provider(other than a service associated with a service to which items 235 to 240 or 735 to 758 of the general medical services table apply) NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
92059	$65.65	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician) to review or coordinate a review of:(a) a GP management plan prepared by a medical practitioner (or an associated medical practitioner) to which item 721 or item 229 of the general medical services table or item 92024, 92055, 92068 or 92099 applies; or(b) team care arrangements which have been coordinated by the medical practitioner (or an associated medical practitioner) to which items 230 or 723 of the general medical services table or item 92025, 92056, 92069 or 92100 applies NOTE: It is a legislative requirement thatthis service must be performed by the patient’s usual medical practitioner (please see Note AN.1.1 for the definition of ‘patient’s usual medical practitioner’ as some exemptions do apply).
92112	$81.70	Telehealth attendance, by a general practitioner who has not undertaken mental health skills training (and not including a specialist or consultant physician), of at least 20 minutes but less than 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient.
92113	$120.25	Telehealth attendance, by a general practitioner who has not undertaken mental health skills training (and not including a specialist or consultant physician), of at least 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient.
92114	$81.70	Telehealth attendance by a general practitionerto review a GP mental health treatment plan which the general practitioner, or an associated general practitioner has prepared, or to review a Psychiatrist Assessment and Management Plan.
92115	$81.70	Telehealth attendance by a general practitioner in relation to a mental disorder and of at least 20 minutes in duration, involving taking relevant history and identifying the presenting problem (to the extent not previously recorded), providing treatment and advice and, if appropriate, referral for other services or treatments, and documenting the outcomes of the consultation.
92116	$103.70	Telehealth attendance, by a general practitioner who has undertaken mental health skills training, of at least 20 minutes but less than 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient.
92117	$152.80	Telehealth attendance, by a general practitioner who has undertaken mental health skills training, of at least 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient.

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
92118	$65.35	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), who has not undertaken mental health skills training, of at least 20 minutes but less than 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient
92119	$96.20	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), who has not undertaken mental health skills training, of at least 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient
92120	$65.35	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), to review a GP mental health treatment plan which he or she, or an associated medical practitioner has prepared, or to review a psychiatrist assessment and management plan
92121	$65.35	Telehealth attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), in relation to a mental disorder and of at least 20 minutes in duration, involving taking relevant history and identifying the presenting problem (to the extent not previously recorded), providing treatment and advice and, if appropriate, referral for other services or treatments, and documenting the outcomes of the consultation
92122	$82.95	Telehealth attendance by a medical practitioner, (not including a general practitioner, specialist or consultant physician),who has undertaken mental health skills training, of at least 20 minutes but less than 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient
92123	$122.25	Telehealth attendance by a medical practitioner, (not including a general practitioner, specialist or consultant physician),who has undertaken mental health skills training, of at least 40 minutes in duration for the preparation of a GP mental health treatment plan for a patient
92126	$81.70	Phone attendance by a general practitioner to review a GP mental health treatment plan which the general practitioner, or an associated general practitioner has prepared, or to review a Psychiatrist Assessment and Management Plan.
92127	$81.70	Phone attendance by a general practitioner in relation to a mental disorder and of at least 20 minutes in duration, involving taking relevant history and identifying the presenting problem (to the extent not previously recorded), providing treatment and advice and, if appropriate, referral for other services or treatments, and documenting the outcomes of the consultation.
92132	$65.35	Phone attendance by a medical practitioner (not including a general practitioner, specialist or consultant physician), to review a GP mental health treatment plan which he or she, or an associated medical practitioner has prepared, or to review a psychiatrist assessment and management plan

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
13200	$3,543.85	Assisted reproductive technologies superovulated treatment cycle proceeding to oocyte retrieval, involving the use of drugs to induce superovulation and including quantitative estimation of hormones, ultrasound examinations, all treatment counselling and embryology laboratory services but excluding artificial insemination, transfer of frozen embryos or donated embryos or ova or a service to which item 13201, 13202, 13203 or 13218 applies, being services rendered during one treatment cycle—initial cycle in a single calendar year
13201	$3,314.90	Assisted reproductive technologies superovulated treatment cycle proceeding to oocyte retrieval, involving the use of drugs to induce superovulation and including quantitative estimation of hormones, ultrasound examinations, all treatment counselling and embryology laboratory services but excluding artificial insemination, transfer of frozen embryos or donated embryos or ova or a service to which item 13200, 13202, 13203 or 13218 applies, being services rendered during one treatment cycle—each cycle after the first in a single calendar year
13202	$530.35	Assisted reproductive technologies superovulated treatment cycle that is cancelled before oocyte retrieval, involving the use of drugs to induce superovulation and including quantitative estimation of hormones and ultrasound examinations, but excluding artificial insemination, transfer of frozen embryos or donated embryos or ova or a service to which item 13200, 13201, 13203 or 13218 applies, being services rendered during one treatment cycle
13203	$554.45	Ovulation monitoring services for artificial insemination or gonadotrophin, stimulated ovulation induction, including quantitative estimation of hormones and ultrasound examinations, being services rendered during one treatment cycle but excluding a service to which item 13200, 13201, 13202, 13212, 13215 or 13218 applies
13207	$125.90	Biopsy of an embryo, from a patient who is eligible for a service described in item 73384 under clause 2.7.3A of the pathology services table (see PR.7.1), for the purpose of providing a sample for pre-implantation genetic testing—applicable to one or more tests performed in one assisted reproductive treatment cycle
13209	$96.45	Planning and management of a referred patient by a specialist for the purpose of treatment by assisted reproductive technologies or for artificial insemination—applicable once during a treatment cycle
13212	$403.80	Oocyte retrieval for the purpose of assisted reproductive technologies—only if rendered in connection with a service to which item 13200 or 13201 applies (Anaes.)
13215	$126.65	Transfer of embryos or both ova and sperm to the uterus or fallopian tubes, excluding artificial insemination—only if rendered in connection with a service to which item 13200, 13201 or 13218 applies, being services rendered in one treatment cycle (Anaes.)
13218	$904.00	Preparation of frozen or donated embryos or donated oocytes for transfer to the uterus or fallopian tubes, by any means and including quantitative estimation of hormones and all treatment counselling but excluding artificial insemination services rendered in one treatment cycle and excluding a service to which item 13200, 13201, 13202, 13203 or 13212 applies (Anaes.)
13221	$57.85	Preparation of semen for the purpose of artificial insemination—only if rendered in connection with a service to which item 13203 applies

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
13241	$968.35	Open surgical testicular sperm retrieval, unilateral, using operating microscope, including the exploration of scrotal contents, with biopsy, for the purposes of intracytoplasmic sperm injection, for male factor infertility, not being a service associated with a service to which item 13218 or 37604 applies (H) (Anaes.)
13251	$476.15	Intracytoplasmic sperm injection for the purpose of assisted reproductive technologies, for male factor infertility, excluding a service to which item 13203 or 13218 applies
13260	$472.75	Processing and cryopreservation of semen for fertility preservation treatment before or after completion of gonadotoxic treatment for malignant or non-malignant conditions, in a post-pubertal male in Tanner stages II-V, up to 60 years old, if the patient is referred by a specialist or consultant physician, initial cryopreservation of semen (not including storage) - one of a maximum of two semen collection cycles per patient in a lifetime.
18264	$114.90	Pudendal nerve or dorsal nerve (or both), injection of an anaesthetic agent, not in association with a service to which an item in Group T8 applies, unless the nerve block is performed using a targeted percutaneous approach
30062	$69.20	Etonogestrel subcutaneous implant, removal of, as an independent procedure (Anaes.)
30626	$775.65	Laparotomy involving division of adhesions in association with another intra-abdominal procedure if the time taken to divide the adhesions is between 45 minutes and 2 hours, on a patient under 10 years of age (Anaes.) (Assist.)
30721	$550.55	Laparotomy or laparoscopy, or laparoscopy converted to laparotomy, with or without associated biopsies, including the division of adhesions (if performed, but only if the time taken to divide adhesions is 45 minutes or less), if no other intra-abdominal procedure is performed (Anaes.) (Assist.)
30724	$596.65	Laparotomy or laparoscopy with division of adhesions, lasting more than 45 minutes but less than 2 hours, performed either:(a) as a primary procedure; or(b) when the division of adhesions is performed in conjunction with another primary procedure—to provide access to a surgical field (but excluding mobilisation or normal anatomical dissection of the organ or structure for which the primary procedure is being carried out) (Anaes.) (Assist.)
30725	$1,057.35	Laparotomy or laparoscopy for intestinal obstruction or division of extensive, complex adhesions, lasting 2 hours or more, performed either:a) as a primary procedure; orb) when the division of adhesions is performed in conjunction with another procedure—to provide access to a surgical field, but excluding mobilisation or normal anatomical dissection of the organ or structure for which the other procedure is being carried out (Anaes.) (Assist.)
35500	$92.65	GYNAECOLOGICAL EXAMINATION UNDER ANAESTHESIA, not being a service associated with a service to which another item in this Group applies (Anaes.)
35503	$91.35	Introduction of an intra-uterine device for abnormal uterine bleeding or contraception or for endometrial protection during oestrogen replacement therapy, if the service is not associated with a service to which another item in this Group applies (other than a service described in item 30062, 35506 or 35620) (Anaes.)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
35506	$61.15	Intra-uterine device, removal of under general anaesthesia, for a retained or embedded device, not being a service associated with a service to which another item in this Group applies (other than a service described in item 35503) (Anaes.)
35560	$779.15	Partial or complete vaginectomy, for either or both of the following:(a) deeply infiltrating vaginal endometriosis, if accompanied by histological confirmation from excised tissue;(b) pre-invasive or invasive lesions Not being a service associated with hysterectomy for non invasive indications (H) (Anaes.) (Assist.)
35626	$255.30	Hysteroscopy for investigation of suspected intrauterine pathology, with or without local anaesthesia, including any associated endometrial biopsy, not being a service associated with a service to which item 35630 applies
35630	$208.50	Hysteroscopy for investigation of suspected intrauterine pathology if performed under general anaesthesia, including any associated endometrial biopsy, not being a service associated with a service to which item 35626 applies (H) (Anaes.)
35631	$810.60	Operative laparoscopy, including any of the following:(a) unilateral or bilateral ovarian cystectomy;(b) salpingo-oophorectomy;(c) salpingectomy for tubal pathology (including ectopic pregnancy by tubal removal or salpingostomy, but excluding sterilisation);(d) excision of mild endometriosis;not being a service associated with a service to which any other intraperitoneal or retroperitoneal procedure item (other than item 30724 or 30725) applies (H) (Anaes.) (Assist.)
35632	$1,013.15	Complicated operative laparoscopy, including either or both of the following:(a) excision of moderate endometriosis;(b) laparoscopic myomectomy for a myoma of at least 4cm, including incision and repair of the uterus;not being a service associated with a service to which any other intraperitoneal or retroperitoneal procedure item (other than item 30724 or 30725 or 35658) applies (H) (Anaes.) (Assist.)
35633	$248.35	Hysteroscopy, under visual guidance, including any of the following:(a) removal of an intra-uterine device;(b) removal of polyps by any method;(c) division of minor intrauterine adhesions (Anaes.)
35635	$341.20	Hysteroscopy involving division of:(a) a uterine septum; or(b) moderate to severe intrauterine adhesions (H) (Anaes.)
35636	$493.30	Hysteroscopy, resection of myoma or myoma and uterine septum (if both are performed) (H) (Anaes.)
35637	$463.20	Operative laparoscopy, including any of the following: (a) excision or ablation of minimal endometriosis; (b) division of pathological adhesions; (c) sterilisation by application of clips, division, destruction or removal of tubes; not being a service associated with another laparoscopic procedure (H) NOTE: Strict legal requirements apply in relation to sterilisation procedures on minors. Medicare benefits are not payable for services not rendered in accordance with relevant Commonwealth and State and Territory law. Observe the explanatory note before submitting a claim. (Anaes.) (Assist.)
35641	$1,415.70	Severe endometriosis, laparoscopic resection of, involving 2 of the following procedures:(a) resection of the pelvic side wall including dissection of endometriosis or scar tissue from the ureter;(b) resection of the Pouch of Douglas; (c) resection of an ovarian endometrioma greater than 2 cm in diameter;(d) dissection of bowel from uterus from the level of the endocervical junction or above (H) (Anaes.) (Assist.)
35653	$768.70	Hysterectomy, abdominal, with or without removal of fallopian tubes and ovaries (H) (Anaes.) (Assist.)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
35657	$768.70	Hysterectomy, vaginal, with or without uterine curettage, inclusive of posterior culdoplasty, not being a service associated with a service to which item 35673 applies (H) (Anaes.) (Assist.)
35658	$474.05	Uterus (at least equivalent in size to a 10 week gravid uterus), debulking of, prior to vaginal or laparoscopic removal at hysterectomy or myoma of at least 4 cm removed by laparoscopy when retrieved from the abdomen (H) (Anaes.) (Assist.)
35661	$1,921.90	Hysterectomy, abdominal, that concurrently requires extensive retroperitoneal dissection with exposure of one or both ureters and complex side wall dissection, including when performed with one or more of the following procedures:(a) salpingectomy;(b) oophorectomy;(c) excision of ovarian cyst(H) (Anaes.) (Assist.)
35669	$2,109.05	Hysterectomy, peripartum, performed for histologically proven placenta increta or percreta, or placenta accreta, if the patient has been referred to another practitioner for the management of severe intractable peripartum haemorrhage (H) (Anaes.) (Assist.)
35671	$1,654.45	Hysterectomy, peripartum, for ongoing intractable haemorrhage where other haemorrhage control techniques have failed, for the purpose of providing lifesaving emergency treatment, not being a service associated with a service to which item 35667, 35668 or 35669 applies (H) (Anaes.) (Assist.)
35673	$863.30	Hysterectomy, vaginal, with or without uterine curettage, with salpingectomy, oophorectomy or excision of ovarian cyst, one or more, one or both sides, inclusive of a posterior culdoplasty, not being a service associated with a service to which item 35657 applies (H) (Anaes.) (Assist.)
35694	$726.40	Tuboplasty (salpingostomy or salpingolysis), unilateral or bilateral, one or more procedures (H) (Anaes.) (Assist.)
35697	$1,077.95	Microsurgical or laparoscopic tuboplasty (salpingostomy, salpingolysis or tubal implantation into uterus), UNILATERAL or BILATERAL, 1 or more procedures (Anaes.) (Assist.)
35700	$831.80	FALLOPIAN TUBES, unilateral microsurgical or laparoscopic anastomosis of (H) (Anaes.) (Assist.)
35703	$76.90	HYDROTUBATION OF FALLOPIAN TUBES as a nonrepetitive procedure (Anaes.)
35717	$971.90	Laparotomy, involving oophorectomy, salpingectomy, salpingo-oophorectomy, removal of ovarian, parovarian, fimbrial or broad ligament cyst—one or more such procedures, unilateral or bilateral, including adhesiolysis, for benign disease (including ectopic pregnancy by tubal removal or salpingostomy), not being a service associated with hysterectomy (H) (Anaes.) (Assist.)
35750	$893.85	Hysterectomy, laparoscopic assisted vaginal, by any approach, including any endometrial sampling, with or without removal of the tubes or ovarian cystectomy or removal of the ovaries and tubes due to other pathology, not being a service associated with a service to which item 35595 or 35673 applies. (H) (Anaes.) (Assist.)
35751	$893.85	Hysterectomy, laparoscopic, by any approach, including any endometrial sampling, with or without removal of the tubes, not being a service associated with a service to which item 35595 applies (H) (Anaes.) (Assist.)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
35753	$988.35	Hysterectomy, complex laparoscopic, by any approach, including endometrial sampling, with either or both of the following procedures:(a) unilateral or bilateral salpingo-oophorectomy (excluding salpingectomy);(b) excision of moderate endometriosis or ovarian cyst;including any associated laparoscopy, not being a service associated with a service to which item 35595 applies (H) (Anaes.) (Assist.)
35754	$1,909.85	Hysterectomy, complex laparoscopic, by any approach, that concurrently requires either extensive retroperitoneal dissection or complex side wall dissection, or both, with any of the following procedures (if performed):(a) endometrial sampling; (b) unilateral or bilateral salpingectomy, oophorectomy or salpingo-oophorectomy;(c) excision of ovarian cyst; (d) any other associated laparoscopy; not being a service associated with a service to which item 35595 or 35641 applies (H) (Anaes.) (Assist.)
55038	$122.40	Urinary tract, ultrasound scan of, if: (a) the service is not solely a transrectal ultrasonic examination of any of the following: (i) prostate gland; (ii) bladder base; (iii) urethra; and (b) within 24 hours of the service, a service mentioned in item 55036 or 55065 is not performed on the same patient by the providing practitioner (R)
55039	$42.40	Urinary tract, ultrasound scan of, if the service is not solely a transrectal ultrasonic examination of any of the following: (a) prostate gland; (b) bladder base; (c) urethra (NR)
55054	$122.40	Ultrasonic cross-sectional echography, in conjunction with a surgical procedure (other than a procedure to which item 55848 or 55850 applies) using interventional techniques, not being a service associated with a service to which any other item in this Group applies (R)
55065	$110.20	Pelvis, ultrasound scan of, by any or all approaches, if:(a) the service is not solely a service to which an item (other than item 55736 or 55739) in Subgroup 5 of this Group applies ora transrectal ultrasonic examination of any of the following: prostate gland; bladder base; urethra; and (b) within 24 hours of the service, a service mentioned in item 55038 is not performed on the same patient by the providing practitioner (R)
55068	$39.15	Pelvis, ultrasound scan of, by any or all approaches, if the service is not solely a service to which an item (other than item 55736 or 55739) in Subgroup 5 of this Group applies or a transrectal ultrasonic examination of any of the following:(i) prostate gland;(ii) bladder base;(iii) urethra (NR)
55084	$110.20	Urinary bladder, ultrasound scan of, by any or all approaches, if within 24 hours of the service, a service mentioned in item 11917, 55036, 55038, 55065, 55600 or 55603 is not performed on the same patient by the providing practitioner (R)
55085	$38.15	Urinary bladder, ultrasound scan of, by any or all approaches, if within 24 hours of the service, a service mentioned in item 11917, 55037, 55039, 55068, 55600 or 55603 is not performed on the same patient by the providing practitioner (NR)
55736	$142.40	Pelvis, ultrasound scan of, in association with saline infusion of the endometrial cavity, by any or all approaches, if a previous transvaginal ultrasound has revealed an abnormality of the uterus or fallopian tube (R)
55739	$63.90	Pelvis, ultrasound scan of, in association with saline infusion of the endometrial cavity, by any or all approaches, if a previous transvaginal ultrasound has revealed an abnormality of the uterus or fallopian tube (NR)
56409	$280.35	Computed tomography—scan of pelvis only (iliac crest to pubic symphysis) without intravenous contrast medium not being a service associated with a service to which item 56401 applies (R) (Anaes.)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
56412	$403.70	Computed tomography—scan of pelvis only (iliac crest to pubic symphysis), with intravenous contrast medium and with any scans of pelvis (iliac crest to pubic symphysis) before intravenous contrast injection, when undertaken, not being a service to which item 56407 applies (R) (Anaes.)
56501	$431.60	Computed tomography—scan of upper abdomen and pelvis without intravenous contrast medium, not for the purposes of virtual colonoscopy and not being a service to which item 56801 or 57001 applies(R) (Anaes.)
63440	$441.45	MRI—scan of person under the age of 16 for pelvic or abdominal mass (R) (Contrast) (Anaes.)
63563	$441.45	MRI scan of the pelvis or abdomen, if the request for the scan identifies that the investigation is for: (a) sub-fertility that requires one or more of the following: (i) an investigation of suspected Mullerian duct anomaly seen in pelvic ultrasound or hysterosalpingogram; (ii) an assessment of uterine mass identified on pelvic ultrasound before consideration of surgery; (iii) an investigation of recurrent implantation failure in IVF (2 or more embryo transfer cycles without viable pregnancy); or (b) surgical planning of a patient with known or suspected deep endometriosis involving the bowel, bladder or ureter (or any combination of the bowel, bladder or ureter), where the results of pelvic ultrasound are inconclusive Applicable not more than once in a 2 year period (R) (Contrast) (Anaes.)
10953	$70.95	Exercise physiology health service provided to a patient by an eligible exercise physiologist if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient’s medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan as part of the management of the patient’s chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or items 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10954	$70.95	Dietetics health service provided to a patient by an eligible dietitian if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient’s medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan as part of the management of the patient’s chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10955	$55.65	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; if the conference lasts for at least 15 minutes, but for less than 20 minutes (other than a service associated with a service to which another item in this Group applies)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
10956	$70.95	Mental health service provided to a patient by an eligible mental health worker if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient’s medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan as part of the management of the patient’s chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10957	$95.45	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; if the conference lasts for at least 20 minutes, but for less than 40 minutes (other than a service associated with a service to which another item in this Group applies)
10958	$70.95	Occupational therapy health service provided to a patient by an eligible occupational therapist if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient’s medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan as part of the management of the patient’s chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10959	$158.80	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in: (a) a community case conference; or (b) a multidisciplinary case conference in a residential aged care facility; if the conference lasts for at least 40 minutes (other than a service associated with a service to which another item in this Group applies)
10960	$70.95	Physiotherapy health service provided to a patient by an eligible physiotherapist if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient’s medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan as part of the management of the patient’s chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
10964	$70.95	Chiropractic health service provided to a patient by an eligible chiropractor if: (a) the service is provided to a patient who has: (i) a chronic condition; and(ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient's medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient's Team Care Arrangements or multidisciplinary care plan as part of the management of the patient's chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10966	$70.95	Osteopathy health service provided to a patient by an eligible osteopath if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient's medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient's Team Care Arrangements or multidisciplinary care plan as part of the management of the patient's chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
10968	$70.95	Psychology health service provided to a patient by an eligible psychologist if: (a) the service is provided to a patient who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (other than a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the patient is a resident of an aged care facility, the patient's medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the patient's Team Care Arrangements or multidisciplinary care plan as part of the management of the patient's chronic condition and complex care needs; and (c) the service is of at least 20 minutes duration; to a maximum of 5 services (including any services to which this item or any other item in this Subgroup or item 93000 or 93013 in the Telehealth and Telephone Determination applies) in a calendar year
82001	$55.65	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in a community case conference if the conference lasts for at least 15 minutes, but for less than 20 minutes (other than a service associated with a service to which another item in this Group applies)
82002	$95.45	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in a community case conference if the conference lasts for at least 20 minutes, but for less than 40 minutes (other than a service associated with a service to which another item in this Group applies)
82003	$158.80	Attendance by an eligible allied health practitioner, as a member of a multidisciplinary case conference team, to participate in a community case conference if the conference lasts for at least 40 minutes (other than a service associated with a service to which another item in this Group applies)

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
82005	$100.20	Speech pathology health service provided to a patient aged under 25 years by an eligible speech pathologist if: (a) the patient was referred by an eligible medical practitioner, or by an eligible allied health practitioner following referral by an eligible medical practitioner, to: (i) assist the eligible medical practitioner with diagnostic formulation where the patient has a suspected complex neurodevelopmental disorder or eligible disability; or (ii) contribute to the patient's treatment and management plan developed by the referring eligible medical practitioner where a complex neurodevelopmental disorder (such as autism spectrum disorder) or eligible disability is confirmed; and (b) the service is provided to the patient individually and in person; and (c) the service is at least 50 minutes duration Up to 4 services to which this item or any of items 82000, 82010, 82030, 93032, 93033, 93040 or 93041 apply may be provided to the same patient on the same day
82010	$100.20	Occupational therapy health service provided to a patient aged under 25 years by an eligible occupational therapist if: (a) the patient was referred by an eligible medical practitioner, or by an eligible allied health practitioner following referral by an eligible medical practitioner, to: (i) assist the eligible medical practitioner with diagnostic formulation where the patient has a suspected complex neurodevelopmental disorder or eligible disability; or (ii) contribute to the patient's treatment and management plan developed by the referring eligible medical practitioner where a complex neurodevelopmental disorder (such as autism spectrum disorder) or eligible disability is confirmed; and (b) the service is provided to the patient individually and in person; and (c) the service is at least 50 minutes duration Up to 4 services to which this item or any of items 82000, 82005, 82030, 93032, 93033, 93040 or 93041 apply may be provided to the same patient on the same day
82015	$113.65	Psychology health service provided to a patient aged under 25 years for the treatment of a diagnosed complex neurodevelopmental disorder (such as autism spectrum disorder) or eligible disability by an eligible psychologist, if: (a) the patient has a treatment and management plan in place and has been referred by an eligible medical practitioner for a course of treatment consistent with that treatment and management plan; and (b) the service is provided to the patient individually and in person; and (c) the service is at least 30 minutes duration; and (d) on the completion of the course of treatment, the eligible psychologist gives a written report to the referring eligible medical practitioner on assessments (if performed), treatment provided and recommendations on future management of the patient's condition Up to 4 services to which this item or any of items 82020, 82025, 82035, 93035, 93036, 93043 or 93044 apply may be provided to the same patient on the same day
91178	$31.05	Telehealth attendance by a participating nurse practitioner lasting less than 20 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a short history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.
91179	$58.85	Telehealth attendance by a participating nurse practitioner lasting at least 20 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a detailed history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
91180	$86.80	Telehealth attendance by a participating nurse practitioner lasting at least 40 minutes if the attendance includes any of the following that are clinically relevant: (a) taking an extensive history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.
91189	$31.05	Phone attendance by a participating nurse practitioner lasting less than 20 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a short history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.
91190	$58.85	Phone attendance by a participating nurse practitioner lasting at least 20 minutes if the attendance includes any of the following that are clinically relevant: (a) taking a detailed history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.
91191	$86.80	Phone attendance by a participating nurse practitioner lasting at least 40 minutes if the attendance includes any of the following that are clinically relevant: (a) taking an extensive history; (b) arranging any necessary investigation; (c) implementing a management plan; (d) providing appropriate preventive health care.
93000	$70.95	Telehealth attendance by an eligible allied health practitioner if: (a) the service is provided to a person who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (including a general practitioner, but not a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the person is a resident of an aged care facility, the person's medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the person's Team Care Arrangements or multidisciplinary care plan as part of the management of the person's chronic condition and complex care needs; and (c) the person is referred to the eligible allied health practitioner by the medical practitioner using a referral form that has been issued by the Department or a referral form that contains all the components of the form issued by the Department; and (d) the service is provided to the person individually; and (e) the service is of at least 20 minutes duration; and (f) after the service, the eligible allied health practitioner gives a written report to the referring medical practitioner mentioned in paragraph (c): (i) if the service is the only service under the referral—in relation to that service; or (ii) if the service is the first or last service under the referral—in relation to that service; or (iii) if neither subparagraph (i) nor (ii) applies but the service involves matters that the referring medical practitioner would reasonably expect to be informed of —in relation to those matters; to a maximum of 5 services (including any services to which this item, item 93013 or any item in Subgroup 1 of Group M3 of the Allied Health Determination applies) in a calendar year

MBS Item	2024 MBS Fee	Full MBS item descriptor including time requirements where applicable
93013	$70.95	Phone attendance by an eligible allied health practitioner if: (a) the service is provided to a person who has: (i) a chronic condition; and (ii) complex care needs being managed by a medical practitioner (including a general practitioner, but not a specialist or consultant physician) under both a GP Management Plan and Team Care Arrangements or, if the person is a resident of an aged care facility, the person's medical practitioner has contributed to a multidisciplinary care plan; and (b) the service is recommended in the person's Team Care Arrangements or multidisciplinary care plan as part of the management of the person's chronic condition and complex care needs; and (c) the person is referred to the eligible allied health practitioner by the medical practitioner using a referral form that has been issued by the Department or a referral form that contains all the components of the form issued by the Department; and (d) the service is provided to the person individually; and (e) the service is of at least 20 minutes duration; and (f) after the service, the eligible allied health practitioner gives a written report to the referring medical practitioner mentioned in paragraph (c): (i) if the service is the only service under the referral—in relation to that service; or (ii) if the service is the first or last service under the referral—in relation to that service; or (iii) if neither subparagraph (i) nor (ii) applies but the service involves matters that the referring medical practitioner would reasonably expect to be informed of —in relation to those matters; to a maximum of 5 services (including any services to which this item, item 93000 or any item in Subgroup 1 of Group M3 of the Allied Health Determination applies) in a calendar year
93201	$16.15	Telehealth attendance provided by a practice nurse or an Aboriginal and Torres Strait Islander health practitioner to a person with a chronic disease if: (a) the service is provided on behalf of and under the supervision of a medical practitioner; and (b) the person has a GP management plan, team care arrangements or multidisciplinary care plan in place and the service is consistent with the plan or arrangements.
93203	$16.15	Phone attendance provided by a practice nurse or an Aboriginal and Torres Strait Islander health practitioner to a person with a chronic disease if: (a) the service is provided on behalf of and under the supervision of a medical practitioner; and (b) the person has a GP management plan, team care arrangements or multidisciplinary care plan in place and the service is consistent with the plan or arrangements.