Endometriosis

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About

This web report is part of Australian Centre for Monitoring Population Health

Endometriosis is an inflammatory condition that can be painful, affect fertility and lead to reduced participation in school, work and social activities. Around 1 in 7 women born in 1973–78 were diagnosed with endometriosis by age 44–49.

This report brings together the latest data to highlight the impact of endometriosis in Australia. It includes information on prevalence, hospitalisations, emergency department presentations, burden of disease and health system expenditure.

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Findings from this report:

- 18 out of every 1,000 hospitalisations among females aged 15–44 were related to endometriosis

- The median age of endometriosis-related hospitalisations is decreasing

- The rate of endometriosis hospitalisations has doubled among females aged 20–24 in the past decade

- Endometriosis is the 3rd leading cause of non-fatal disease burden due to female reproductive and maternal conditions

Summary

On this page:

Endometriosis

Endometriosis is a disease where tissue similar to the lining of the uterus grows in other parts of the body (Endometriosis Australia 2023). It is an inflammatory condition that can be painful, affect fertility and lead to reduced participation in school, work and social activities.

Symptoms of endometriosis vary between individuals. Some people experience no symptoms, while others experience severe pain, heavy menstrual bleeding, bleeding between periods, abdominal bloating, fatigue, anxiety and depression, among other symptoms (Jean Hailes for Women's Health 2023).

There is no known cure for endometriosis. Treatments are available to manage the symptoms associated with endometriosis and improve quality of life.

For more information on endometriosis see What is endometriosis?.

How common is endometriosis?

The Australian Longitudinal Study on Women's Health (ALSWH) is a national study focusing on women's health. The ALSWH provides information about endometriosis among women in 2 specific cohorts–those born in 1973–78 and those born in 1989–95.

According to the ALSWH, around 1 in 7 (14%) women born in 1973–1978 were estimated to have been diagnosed with endometriosis by age 44–49. Among a younger cohort of women born in 1989–95, 8.8% were estimated to have been diagnosed with endometriosis by age 26–31.

As expected, the cumulative incidence of endometriosis increased with age as women have more time to receive a diagnosis (Figure 1). Of women in the 1989–95 cohort who had turned 31, 9.2% were estimated to have been diagnosed with endometriosis compared with 6.9% of women born in 1973–78 at this age. These differences may reflect increased awareness of endometriosis among the general public and health professionals, leading to increased diagnosis among women born more recently.

See How common is endometriosis? For more information on the incidence and prevalence of endometriosis.

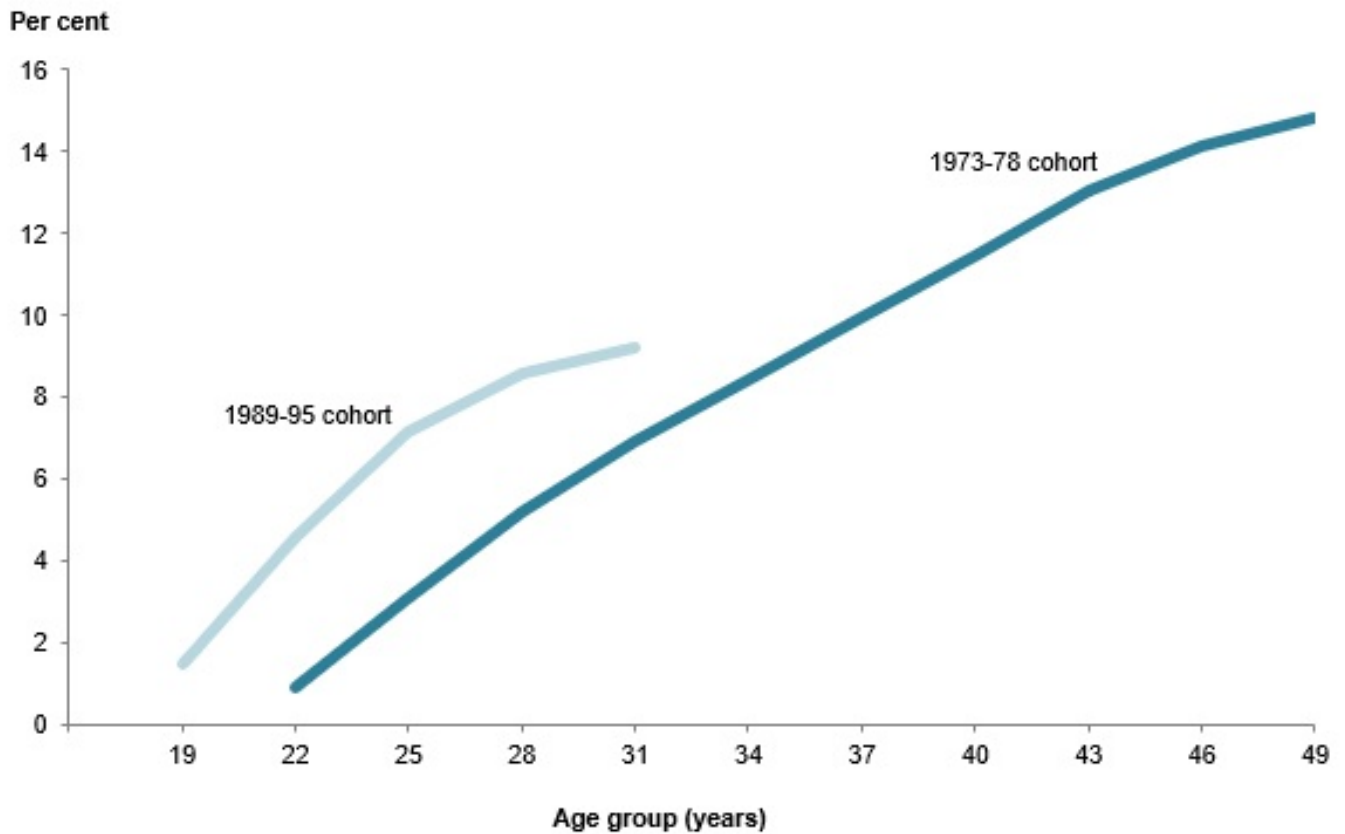**Figure 1: Cumulative incidence of endometriosis, by cohort and age**

Chart: AIHW. Source: Australian Longitudianal Study on Women's Health (ALSWH).

Hospitalisations

According to the AIHW National Hospital Morbidity Database (NHMD), there were 40,500 endometriosis-related hospitalisations in 2021–22. This represents 312 hospitalisations per 100,000 females. Around half (52%) of endometriosis-related hospitalisations in 2021–22 had endometriosis as the principal diagnosis.

Most endometriosis-related hospitalisations (82% in 2021–22) are among females aged 15–44 (Figure 2), which are generally regarded as a woman's reproductive years. This represents 18 out of every 1,000 hospitalisations among females in this age group.

The rate of endometriosis hospitalisations has doubled among females aged 20–24 in the past decade, from 330 hospitalisations per 100,000 females in 2011–12 to 660 per 100,000 in 2021–22. This was particularly driven by the increase in the rate of hospitalisations in private hospitals in this period, which more than doubled from 175 to 425 hospitalisations per 100,000 females.

Compared with all female hospitalisations in 2021–22, endometriosis-related hospitalisations were more likely to be partly or fully funded by private health insurance, self-funded, or occur in a private hospital.

See Hospitalisations for more information on endometriosis-related hospitalisations.

Figure 2: Age profile of endometriosis-related hospitalisations, 2011-12 to 2021-22

Alt text: This interactive line chart shows the number, crude rate, and total bed days of endometriosis hospitalisations by age group, hospital sector and year. In 2021–22 the overall number of hospitalisations, rate of hospitalisation and total bed days were highest among females aged 35-39.
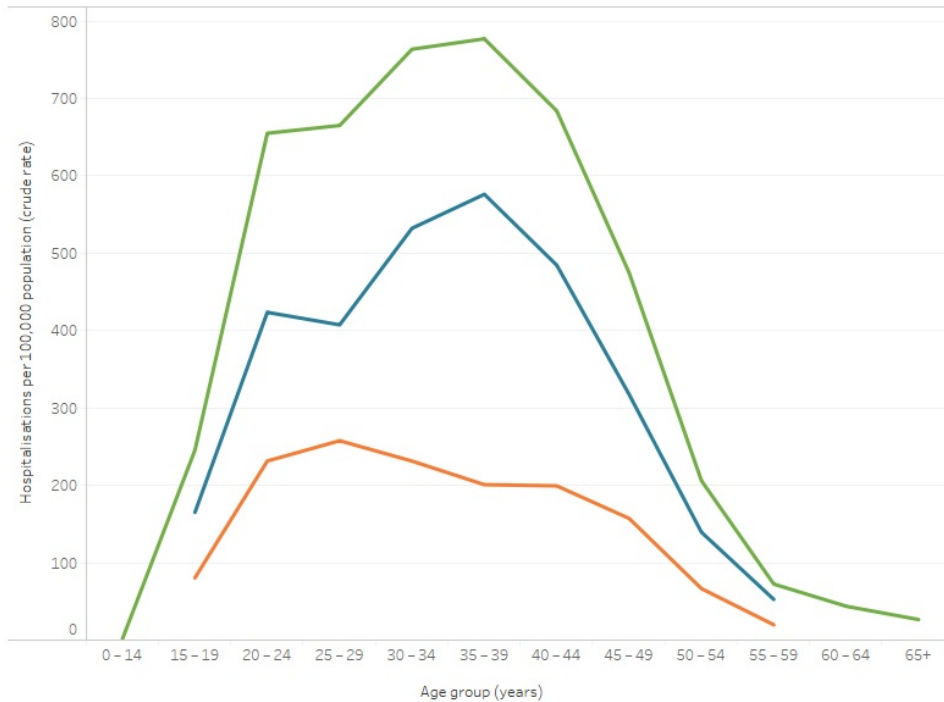
Select diagnosis scope
◉ Any diagnosis of endometriosis
◯ Principal diagnosis of endometriosis

Select hospital sector
All

Hospital sector
■ Private hospitals   ■ Total
■ Public hospitals

Emergency Department presentations

There were more than 3,600 endometriosis-related emergency department (ED) presentations in 2021–22. This represents around 28 presentations per 100,000 females.

Most endometriosis-related ED presentations were among females aged 15–44 (Figure 3). The rate of endometriosis-related ED presentations was highest in the 20–24 age group.

The number and rate of ED presentations due to endometriosis has fluctuated between 2018–19 and 2021–22, peaking at 3,700 presentations in 2020–21.

See Emergency Department presentations for more information on endometriosis-related ED presentations.

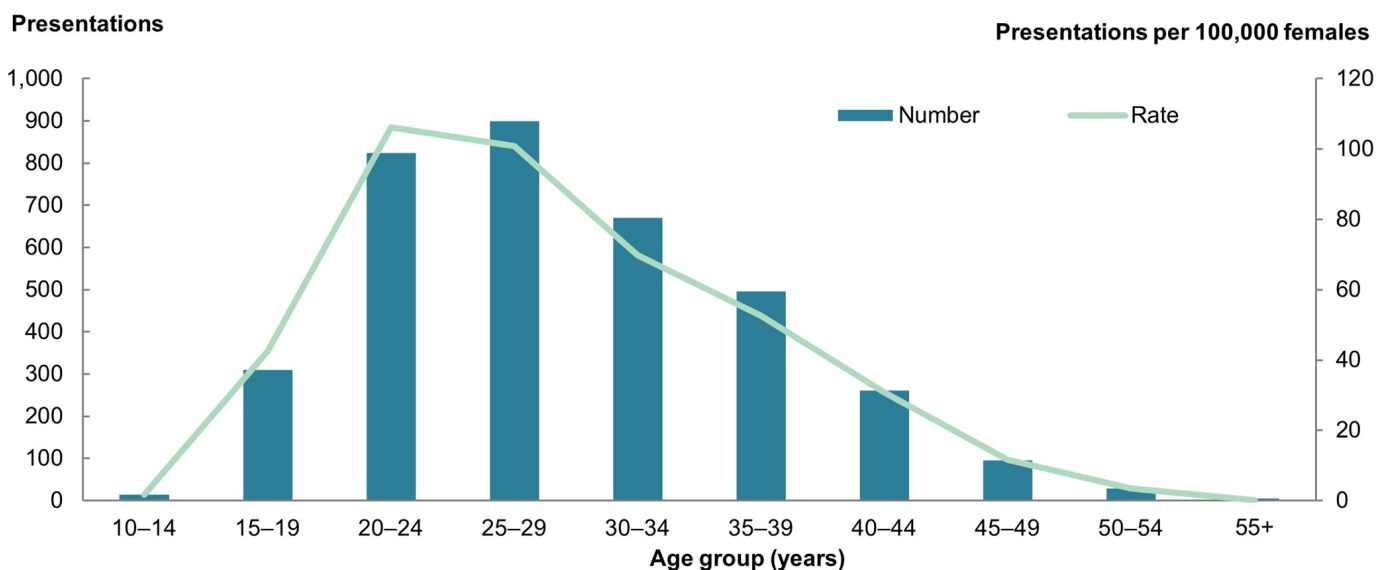**Figure 3: Number and rate of endometriosis-related emergency department presentations, by age group, 2021–22**

Chart: AIHW. Source: AIHW National Non-admitted Patient Emergency Department Care (NNAPEDC).

Burden of disease due to endometriosis

Burden of disease is the quantified impact of a disease or injury on a population, using the disability-adjusted life years (DALYs) measure. For endometriosis, there is no burden due to dying prematurely, so only non-fatal burden (YLD) is reported.

In 2023, The Australian Burden of Disease Study found that there were 8,213 YLD from endometriosis in Australia, a rate of 0.61 per 1,000 females (AIHW 2023a). The disease burden due to endometriosis is highest among females aged 30–34 with a rate of 1.71 YLD per 1,000 females.

Endometriosis is the third leading cause of non-fatal disease burden among females due to reproductive and maternal conditions (13%), after genital prolapse (52%) and polycystic ovarian syndrome (26%).

See Burden of disease for more information on the burden of disease due to endometriosis.

Economic burden of endometriosis

According to the Australian Disease Expenditure Study, an estimated $247.2 million was spent on endometriosis in the Australian health system in 2020–21 (AIHW 2023b). The majority (86%) of endometriosis expenditure was attributed to hospitals (including public hospital admitted patient, outpatient and emergency department services and private hospital services).

About 83% of total expenditure on endometriosis was attributed to females aged 15–44 years. Females aged 35–39 years had the highest expenditure amongst all age groups, accounting for around 20% of total endometriosis expenditure.

The cost of disease is not just financial: being unwell has other effects on quality of life, affecting people's ability to work or do the activities they enjoy. One Australian study estimated the overall cost of endometriosis was $30,900 per person with the condition in 2017, with 84% of this attributed to lost productivity (Armour et al. 2019).

See Economic burden for more information on endometriosis expenditure.

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Endometriosis

On this page

- What is endometriosis?
- What causes endometriosis?
- What are the symptoms of endometriosis?
- Diagnosing endometriosis
- References

What is endometriosis?

Endometriosis is a disease where tissue similar to the lining of the uterus grows in other parts of the body (Endometriosis Australia 2023). Endometriosis most often affects the reproductive organs but can also be found in other areas, such as around the bowel and bladder. These tissues are collectively known as endometriosis. Endometriosis can cause inflammation and scarring, which can lead to painful 'adhesions' joining together pelvic organs which are normally separate.

Endometriosis is a progressive chronic condition. Recent research views endometriosis as an inflammatory, multi-system illness (Saunders et al. 2021; Taylor et al. 2021; Zondervan et al. 2020). There is some evidence to suggest associations exist between endometriosis and other chronic conditions, such as selected cancers and cardiovascular disease (Shafrir et al. 2018).

What causes endometriosis?

The cause of endometriosis is unclear. A family history of endometriosis appears to increase the risk of developing the condition (Jean Hailes for Women's Health 2023a). Other theories that have been suggested throughout the years are metaplasia (the conversion of normal pelvic tissue into endometriosis) and retrograde (backwards) menstruation (Healthdirect 2021). Other contributing factors may include early age at first period, short menstrual cycles, heavy or long periods, older age of first pregnancy, immune system problems, low body weight, and alcohol consumption.

What are the symptoms of endometriosis?

Symptoms of endometriosis vary between individuals. Some people experience no symptoms, while others experience severe pain, heavy menstrual bleeding, bleeding between periods, abdominal bloating, fatigue, anxiety and depression, among other symptoms (Jean Hailes for Women's Health 2023a). Pain is a common symptom and can include abdominal, lower back or pelvic pain, painful menstruation, pain during or after intercourse, pain during ovulation, and pain during urination or defaecation. In some cases endometriosis can affect fertility due to the impact on reproductive organs (Jean Hailes for Women's Health 2023b).

The severity of symptoms does not necessarily reflect the extent of the condition. For example, a person with minimal endometriosis may experience more pain than a person with severe endometriosis (Jean Hailes for Women's Health 2023a).

Symptoms of endometriosis can occur from menarche (start of menstruation) through menopause (WHO 2021). After menopause, symptoms may ease for many but not for all (Jean Hailes for Women's Health 2023a).

Diagnosing endometriosis

There are several systems for classifying endometriosis based on the extent and location of the endometriosis, though none have been universally accepted (RANZCOG 2021). It is recommended that treatment is based on symptoms and an individual's needs, preferences, and priorities for care.

The 'gold standard' for definitive diagnosis of endometriosis is a laparoscopic procedure including biopsy and destruction of endometriotic lesions (RANZCOG 2021). However, other methods may be used to reasonably suspect endometriosis and begin treatment without surgery, known as a 'clinical diagnosis' (Agarwal et al. 2019; Taylor et al. 2018).

Diagnosis of endometriosis is often delayed, with an average of between 6 and 8 years between onset of symptoms and diagnosis (Armour et al. 2020, O'Hara et al. 2022). Nonspecific symptoms, lack of specific biomarkers, lack of awareness of the condition, and stigma and symptom normalisation have been identified as key contributors to the diagnostic delay (Zondervan et al. 2020). In the study which found an average delay of 8 years, this time was comprised of 3 years from symptom onset to seeking medical care, and 5 years from the first medical appointment to a surgical diagnosis of endometriosis (Armour et al. 2020). However, the diagnostic delay appears to be decreasing over time, both for the time to seeking medical care and time to receiving a diagnosis.

The National Action Plan for Endometriosis

The National Action Plan for Endometriosis was launched in 2018 with the goal of 'a tangible improvement in the quality of life for individuals living with endometriosis, including a reduction in the impact and burden of disease at individual and population levels'. The plan has 3 priority areas:

- awareness and education – this involves developing and delivering community awareness campaigns, promoting early education on women's health in schools, improving access to information for people living with endometriosis, and improving awareness and understanding of endometriosis among health professionals
- clinical management and care – this involves developing clinical guidelines and clinical care standards; promoting early access to intervention, care and treatment options; improving affordability, accessibility and consistency of management; ensuring endometriosis is recognised as a chronic condition by all health practitioners; and narrowing the gap in quality of life between people with endometriosis and their peers
- research – this involves building a collaborative environment for endometriosis research, mining existing data and improving data linkage between sources, and conducting further research to understand causes and impacts and progress towards a cure (Department of Health 2018a).

Reducing the prevalence and impact of endometriosis and associated chronic pelvic pain is also listed as a key priority for chronic conditions and preventive health in the National Women's Health Strategy 2020–2030 (Department of Health 2018b).

Endometriosis data by sex and gender

Endometriosis can affect women and girls, transgender, non-binary, and gender-diverse people assigned female at birth (Department of Health 2018). In this report, terminology used to refer to those experiencing endometriosis is based on that used in the underlying data collection.

Australian Longitudinal Study on Women's Health (ALSWH 2020a; ALSWH 2020b)

- 1973–78 cohort: invitations were sent in 1996 based on information from the Medicare database in 1996, where an individual's sex was recorded as female, and their date of birth was between 1973 and 1978.
- 1989–95 cohort: participants were recruited online in 2012 and 2013, mainly from social media. Participants from this cohort were asked their sex in the 2013 survey. It is not known whether participants interpreted this to mean sex at birth or gender identity.
- The gender identity of participants in the study is not known, as this information is not routinely collected. Participants in this study may identify as female or have a different gender identity.

National Hospital Morbidity Data/National Non-admitted Patient Emergency Department Database

- Hospitalisation and emergency department presentation data are based on hospital admissions records. Patients' sex was recorded as 'male', 'female' or 'other'.
- Depending on the practices of the hospital, this may be based on what the patient selected, or how hospital staff completed the record. It may also be based on an existing hospital record for the patient, which may no longer reflect how they identify.
- It is important to note that it is not known if the people completing these records interpreted sex to mean sex at birth or gender identity.
- A small number of hospitalisations/ED presentations (<10) were reported with a sex of 'male' or 'other'. To preserve confidentiality, data presented in this report have been restricted to hospitalisations/ED presentations with a sex of 'female' only. The Estimated Resident Population for Australian females is used for the denominator when calculating rates.

References

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How common is endometriosis?

Page highlights

- Around 1 in 7 (14%) women born in 1973-78 were estimated to have been diagnosed with endometriosis by age 44-49.
- 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).

According to the Australian Longitudinal Study on Women's Health, 14% of women born in 1973-1978 were estimated to have been diagnosed with endometriosis by age 44-49. This comprised an estimated 7.6% with surgically confirmed endometriosis and 6.6% with clinically suspected endometriosis.

Among a younger cohort of women born in 1989-95, 8.8% were estimated to have been diagnosed with endometriosis by age 26-31. This comprised an estimated 3.8% with surgically confirmed endometriosis and 5.0% with clinically suspected endometriosis.

As expected, the cumulative incidence of endometriosis increased with age as women have more time to receive a diagnosis (Figure 1). Of women in the 1989-95 cohort who had turned 31, 9.2% were estimated to have been diagnosed with endometriosis compared with 6.9% of women born in 1973-78 at this age.

Differences between the two cohorts are also evident in the age-specific incidence rates. To date, the peak age-specific incidence occurred at 22 for the 1989-95 cohort, compared with 25 for the 1973-78 cohort.

These differences may reflect increased awareness of endometriosis among the general public and health professionals, leading to increased diagnosis among women born more recently.

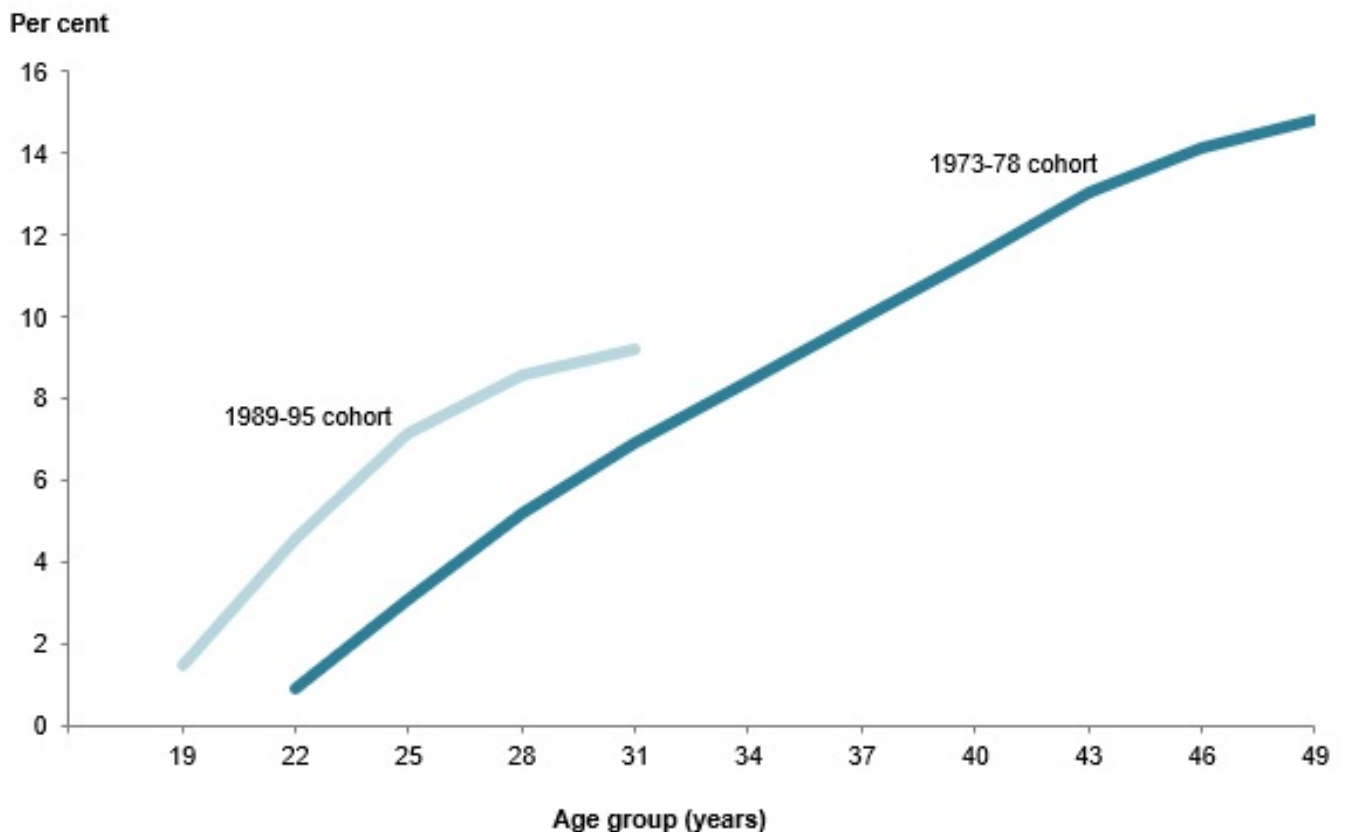**Figure 1: Cumulative incidence of endometriosis, by cohort and age**

Chart: AIHW. Source: Australian Longitudianal Study on Women's Health (ALSWH).

Estimating the prevalence of endometriosis with the Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (ALSWH) is a national study focusing on women's health. The ALSWH provides information about endometriosis among women in 2 specific cohorts – those born in 1973-78 and those born in 1989-95. Researchers from the University of Queensland used data from surveys of women in the study, linked with administrative health data, to estimate the prevalence and cumulative incidence of endometriosis in these cohorts. The estimates were based on:

Other Australian prevalence

There is a lack of comparable Australian prevalence estimates in recent decades. In an earlier Australian study, a questionnaire of around 3,000 female twins aged 18 and over conducted in 1993–1994 found that 7% of respondents had ever had endometriosis (Treloar et al. 1999). The twins were considered representative of the general population, with regard to age, education and marital status.

International prevalence estimates

In international research, the prevalence of endometriosis is estimated to be about 10% among women of reproductive age (WHO 2021; Zondervan et al. 2020). This estimate is based on a United States study conducted from 1976 to 1984 which identified histologic diagnosis of endometriosis among 858 women undergoing vaginal hysterectomy for preoperative diagnoses excluding endometriosis, pelvic pain and adhesions (Wheeler 1989). A more recent United States study involving an online survey of women aged 18–49 estimated the prevalence of diagnosed endometriosis as 6.1% (Fuldeore & Soliman 2017).

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Zondervan KT, Becker CM & Missmer SA (2020) 'Endometriosis', *New England Journal of Medicine,* 382:1244–56. doi:10.1056/NEJMra1810764

Treatment & management

There is no known cure for endometriosis. Treatments are available to manage the symptoms associated with endometriosis and improve quality of life, including:

- pain relievers
- hormonal treatments, including hormonal contraceptives, which suppress ovulation and periods
- surgery for the removal of lesions via laparoscopy (key-hole surgery) or laparotomy (abdominal surgery).

In severe cases, surgery may be performed to remove the uterus (hysterectomy) or remove parts of the bowel affected by endometriosis (The Royal Women's Hospital 2023). In most cases, hysterectomy is performed to treat other causes of uterus pain (for example, adenomyosis), and to prevent possible future regrowth of endometriosis around these organs.

Where endometriosis has contributed to reduced fertility, surgery to remove lesions may be used to improve fertility.

Individuals may also seek treatment from allied health or complementary therapies, such as physiotherapy, acupuncture, traditional Chinese medicine, exercise, and diet modifications. Further research is needed to determine how common these treatments are among people with endometriosis and their efficacy for managing symptoms (RANZCOG 2021).

Primary health care

General practitioners are often the first point of contact for those with suspected endometriosis and are therefore instrumental in identifying symptoms, prescribing medication or providing referrals to specialists for further testing and/or treatment. The management of endometriosis in primary care presents a substantial data gap.

For further information see Data gaps and opportunities.

References

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Treatment & management

On this page

Page highlights

- There were 40,500 endometriosis-related hospitalisations in 2021–22. This represents 312 hospitalisations per 100,000 females.
- 82% of endometriosis-related hospitalisations were amongst females aged 15–44, representing 18 out of every 1,000 hospitalisations in this age group.
- The number of endometriosis-related hospitalisations increased by 43% between 2011–12 and 2021–22, from 28,400 to 40,500 hospitalisations, peaking at 43,800 in 2020–21.
- The rate of endometriosis hospitalisations has doubled among females aged 20–24 in the past decade, from 330 hospitalisations per 100,000 females in 2011–12 to 660 per 100,000 in 2021–22.
- There were just over 1,000 endometriosis-related hospitalisations for First Nations people, representing 2.5% of endometriosis-related hospitalisations.
- In 2021–22, 26% of endometriosis-related hospitalisations were among females born outside of Australia.
- Over two-thirds (68%) of endometriosis-related hospitalisations took place in a private hospital.

Around half (52%) of endometriosis-related hospitalisations in 2021–22 had endometriosis as the principal diagnosis according to the AIHW National Hospital Morbidity Database (NHMD). The remainder had endometriosis as an additional diagnosis only (48%). See _Co-occurring diagnoses_ for information on other diagnoses commonly recorded for endometriosis-related hospitalisations.

About 1 in 3 (33%) hospitalisations with a principal diagnosis of endometriosis also had one or more additional diagnoses of endometriosis.

Endometriosis of the pelvic peritoneum was the most common diagnosis among the hospitalisations, representing 51% of principal diagnoses and 44% of additional diagnoses (Figure 2). This was followed by endometriosis of the uterus (18% of principal and 28% of additional diagnoses), and of the ovary (13% of principal and 19% of additional diagnoses).

Figure 2: Endometriosis-related hospitalisations, by 4th character ICD-10-AM code, 2021–22
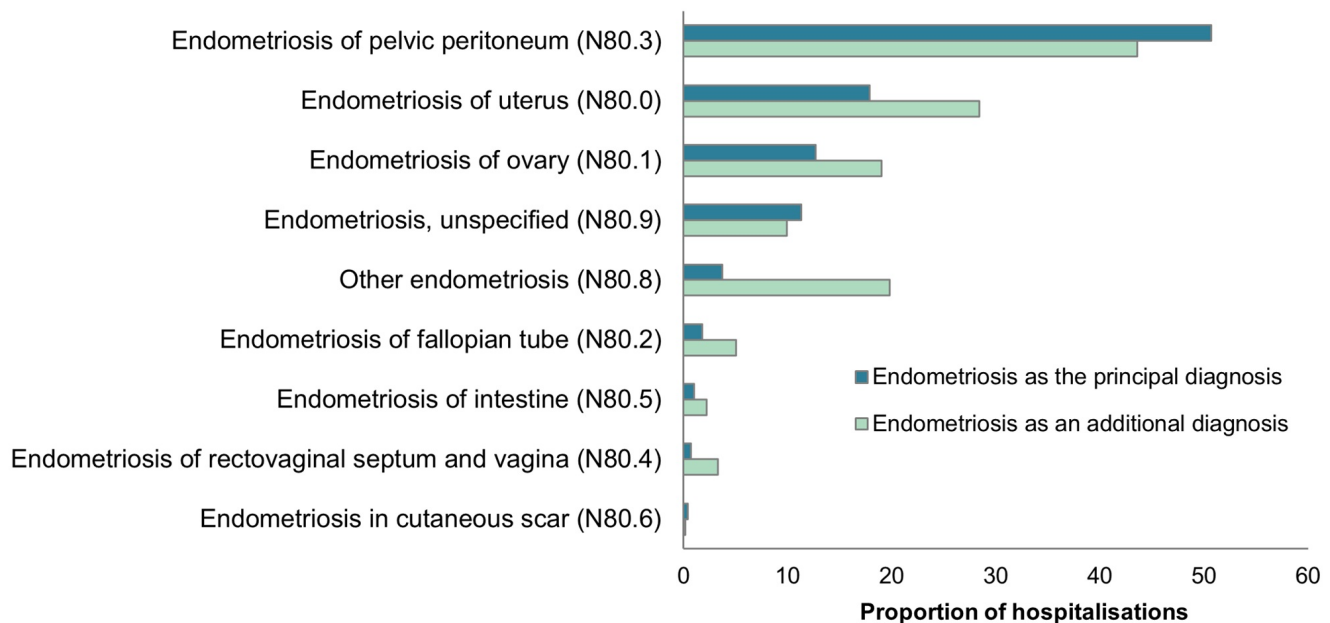
Chart: AIHW. Source: AIHW National Hospital Morbidity Database (NHMD).

Notes

1. *Endometriosis of uterus* (N80.0) includes adenomyosis. *Other endometriosis* (N80.8) includes endometriosis of thorax.
2. The total proportion for endometriosis as an additional diagnosis exceeds 100% as some hospitalisations have more than one additional diagnosis of endometriosis.

What is an endometriosis-related hospitalisation?

- Hospitalisation data presented here are based on admitted patient episodes of care from the National Hospital Morbidity Database (NHMD), including multiple events experienced by the same individual in a given time frame.
- A **separation** is an episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute care to rehabilitation). In this report, separations are referred to as **hospitalisations**.
- **Hospitalisations with endometriosis as the <u>principal diagnosis</u>** are hospitalisations for which endometriosis was determined to be chiefly responsible for occasioning the episode of admitted patient care.
- **Hospitalisations with endometriosis as an <u>additional diagnosis</u> only** are hospitalisations for which another condition was chiefly responsible for the episode of care, but endometriosis was determined to affect patient management.
- Some hospitalisations have endometriosis listed as both a principal and additional diagnosis. These hospitalisations are counted with the principal diagnosis group and excluded from the additional diagnosis group to avoid double counting.
- **Endometriosis-related hospitalisations** are hospitalisations with a principal and/ or additional diagnosis of endometriosis.
- A **procedure** is a clinical intervention that is surgical in nature, carries a procedural risk, carries an anaesthetic risk, requires specialised training and/or requires special facilities or equipment only available in an acute care setting.
- The health classification used for morbidity reporting in Australia is the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) which is used alongside the Australian Classification of Health Interventions (ACHI) which classifies procedures and interventions.

For further information on the NHMD and the methods used in this report, see the Technical notes.

Variation by age

Most endometriosis-related hospitalisations (82% in 2021–22) are among females aged 15-44 (Figure 3), which are generally regarded as a woman's reproductive years. This represents 18 out of every 1,000 hospitalisations among females in this age group. In comparison, 31% of all hospitalisations among females in 2021–22 were for this age group. Endometriosis was the 20th most common reason for hospitalisation among those aged 15-44 years (by principal diagnosis at the ICD-10-AM 3-character level). The most common reasons for hospitalisation among this age group are related to childbirth, procreative management, dialysis, and abdominal and pelvic pain.

There are few endometriosis-related hospitalisations among females aged under 15. The number and the rate of hospitalisations then rise with age to 30-39, before decreasing. There are relatively few hospitalisations among women aged 55 and over, potentially reflecting the decrease in endometriosis symptoms among most women after menopause.

Over the past decade, the rate of endometriosis-related hospitalisations increased across most age groups. The greatest increase was seen among ages 20-24, with the rate doubling between 2011–12 and 2021–22 (from 330 to 660 hospitalisations per 100,000 females). In 2021–22, 21 out of every 1,000 hospitalisations among females aged 20-24 were related to endometriosis. This trend was particularly driven by the

increase in the rate of hospitalisations in private hospitals for women aged 20-24, which more than doubled from 175 to 425 hospitalisations per 100,000 females in this period.

Total bed days mirrors the pattern seen for hospitalisations, with the peak generally among ages 35-39.

Figure 3: Age profile of endometriosis-related hospitalisations, 2011-12 to 2021-22

Alt text: This interactive line chart shows the number, crude rate, and total bed days of endometriosis hospitalisations by age group, hospital sector and year. In 2021-22 the overall number of hospitalisations, rate of hospitalisation and total bed days were highest among females aged 35-39.

Notes
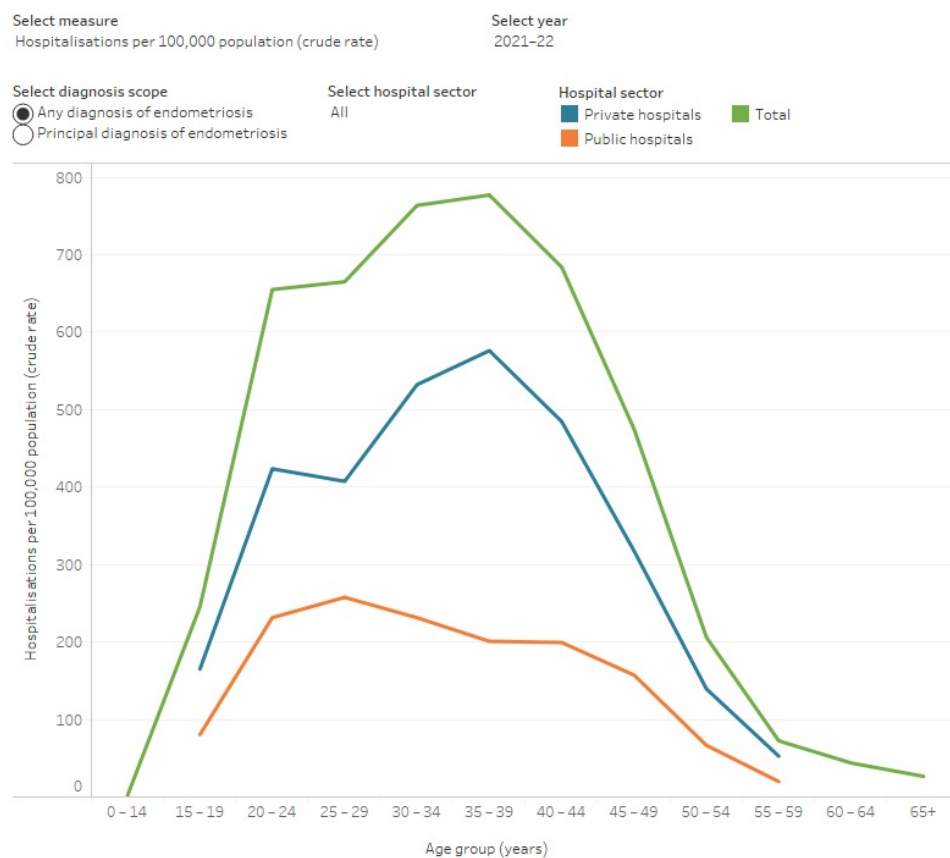
Source: AIHW National Hospital Morbidity Database (NHMD).
https://www.aihw.gov.au

Trends over time

The number of endometriosis-related hospitalisations increased by 43% between 2011-12 and 2021-22, from 28,400 to 40,500 hospitalisations, peaking at 43,800 in 2020-21 (Figure 4). While hospitalisations in Australia are generally increasing over time, growth in the number of endometriosis-related hospitalisations was greater than that seen for all female hospitalisations between 2011-12 and 2021-22 (25%).

The rate of endometriosis-related hospitalisations also increased by 24% during this period, from 250 per 100,000 females in 2011-12 to 310 per 100,000 females in 2021-22. Over the same period, the rate of hospitalisation for all females increased by 9%.

Endometriosis-related hospitalisations increased by an average of 2.2% each year until 2019-20, when they decreased coinciding with the start of the coronavirus (COVID-19) pandemic and a temporary suspension of non-urgent elective surgery. Between 2019-20 and 2021-22, endometriosis-related hospitalisations fluctuated, influenced by the resumption of non-urgent elective surgery, as well as easing of restrictions that were implemented to reduce the spread of the COVID-19 virus more generally. See Impact of COVID-19 on endometriosis-related hospitalisations for further analysis of endometriosis-related hospitalisations during the pandemic period.

Overall, patterns of growth were seen across states and territories and by hospital sector, with slight differences year to year and following the start of the COVID-19 pandemic. In 2021-22, hospitals located in the Australian Capital Territory (ACT) had the highest rate of endometriosis-related hospitalisation (390 per 100,000 population), while hospitals in the Northern Territory had the lowest (170 per 100,000). These rates may be influenced by cross-border patient flows, where patients living in one jurisdiction attend a hospital in another jurisdiction. For example, 19% of total hospitalisations in the ACT in 2021-22 were for patients who lived in New South Wales (AIHW 2023).

Between 2011-12 and 2021-22, the hospitalisation rate in private hospitals increased by 37%, compared with a 4.0% increase in the rate in public hospitals. Most endometriosis-related hospitalisations occur in private hospitals; see Funding source for further analyses.

The median age of endometriosis patients has decreased slightly over the same period, from 37 in 2011-12 to 35 in 2021-22. Efforts to increase awareness of endometriosis among Australian women and medical practitioners may have contributed to this trend through earlier treatment and diagnosis (Armour et al. 2022).

Figure 4: Endometriosis-related hospitalisations, 2011-12 to 2021-22

This interactive line chart shows endometriosis-related hospitalisations by year and by hospital sector. The number and rate of hospitalisations for endometriosis were higher in private hospitals than public hospitals for all years. The median age was younger in public hospitals than private hospitals across all years. Similar patterns were seen for ages 15-44 as with all ages, and for a principal diagnosis of endometriosis as with any diagnosis of endometriosis.
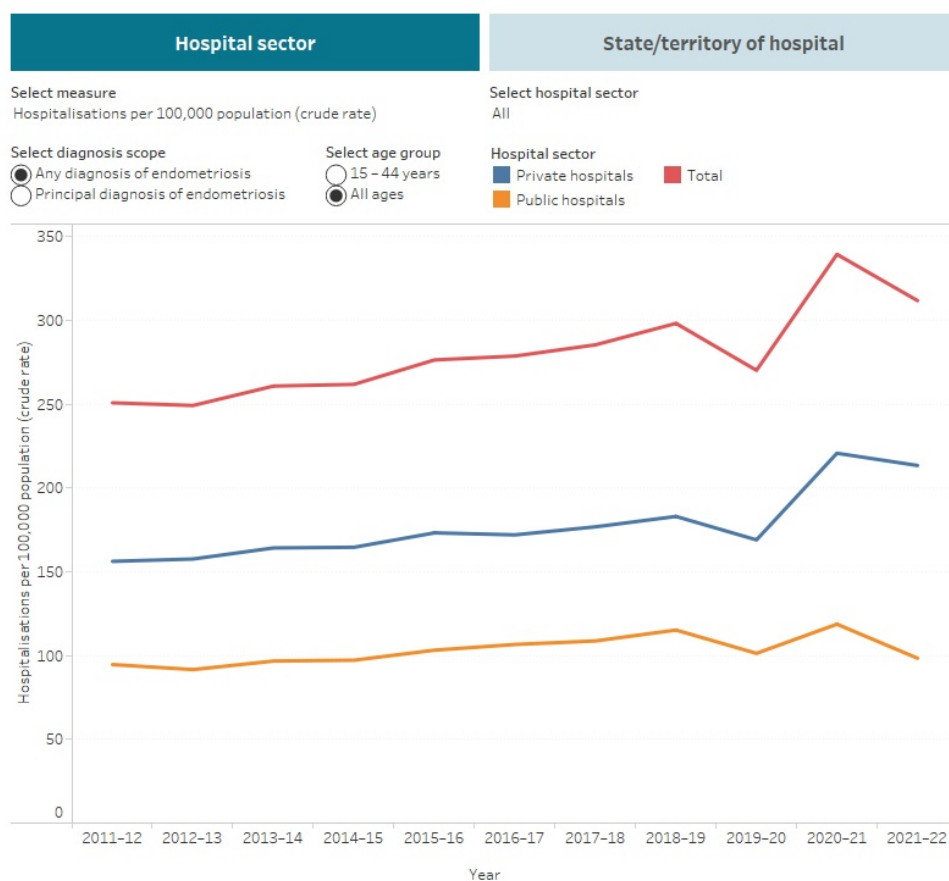
Notes: Rates were calculated using the December estimated resident population for females.
Source: AIHW National Hospital Morbidity Database (NHMD).
https://www.aihw.gov.au

Variation between population groups

In 2021–22, endometriosis-related hospitalisations varied between population groups (Figure 5). These differences could reflect potential variations in access to health services, including different barriers to access, or differences in health-seeking behaviour between population groups, rather than a difference in disease prevalence.

First Nations people

There were just over 1,000 endometriosis-related hospitalisations for Aboriginal and Torres Strait Islander (First Nations) women in 2021-22, representing 330 hospitalisations per 100,000 females. About 2.5% of endometriosis-related hospitalisations were among First Nations women, compared with 5.9% of all female hospitalisations in this period.

The age-standardised rate for endometriosis-related hospitalisations among non-Indigenous Australians was 1.3 times the rate for First Nations women.
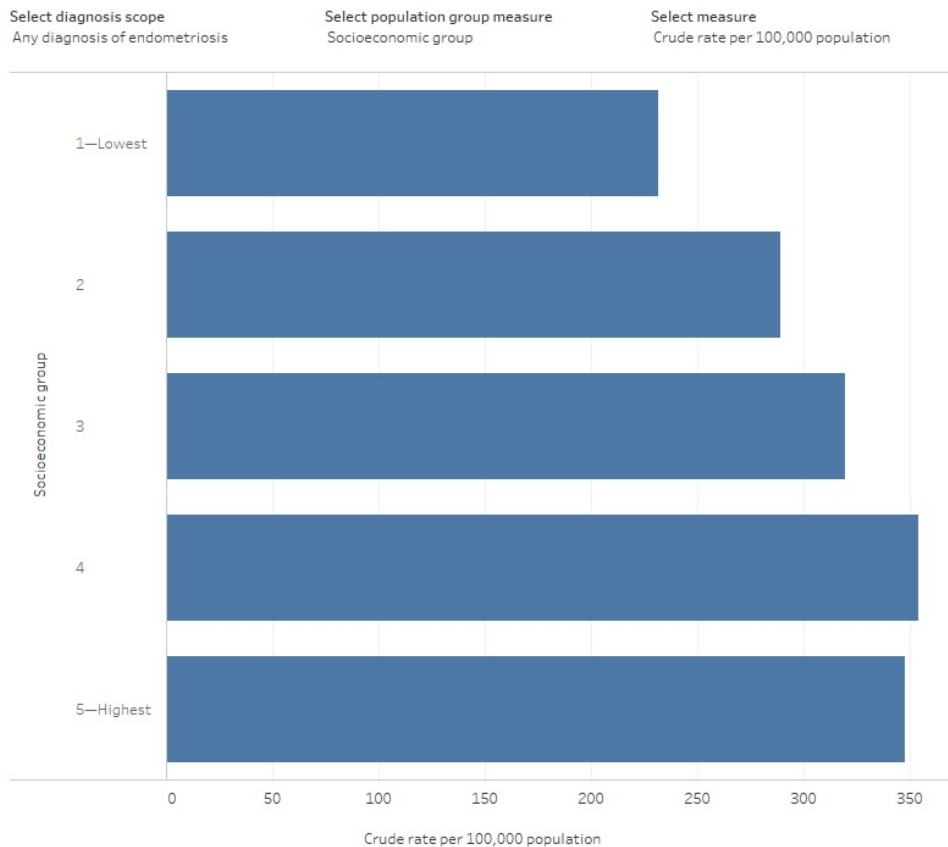
Socioeconomic area

The age-standardised rate for endometriosis-related hospitalisations for patients living in the highest socioeconomic areas was 1.4 times the rate for patients living in the lowest areas. This contrasts with the pattern seen among all female hospitalisations, where the age-standardised rate for patients living in the lowest socioeconomic areas was 1.3 times the rate for patients living in the highest areas.

Remoteness area

The age standardised-rate for endometriosis-related hospitalisations for patients living in *Major cities* was 1.8 times the rate for patients living in *Remote and very remote* areas. This contrasts with the pattern seen for all female hospitalisations, where the age-standardised rate for patients living in *Remote and very remote* areas was 1.8 times the rate for patients living in *Major cities.*

Figure 5: Endometriosis-related hospitalisations, by population group, 2021-22

Alt text: This interactive bar chart shows endometriosis-related hospitalisations by socio-economic group, remoteness area and Indigenous status. The crude rate of endometriosis hospitalisations was highest in the second most advantaged socioeconomic group and lowest in the most disadvantaged group. Crude hospitalisation rates were highest in *Major cities* and lowest in *Remote and very remote* areas. Similar patterns were seen for a principal diagnosis of endometriosis as with any diagnosis of endometriosis.

Select diagnosis scope
Any diagnosis of endometriosis

Select population group measure
Socioeconomic group

Select measure
Crude rate per 100,000 population

Notes

Source: AIHW National Hospital Morbidity Database (NHMD).
https://www.aihw.gov.au

Country of birth

In 2021–22, 26% of endometriosis-related hospitalisations were among females born outside of Australia. This is similar to the proportion for all female hospitalisations (27%), and likely reflects the pattern seen in the general population, with 30% of females born outside of Australia (ABS 2021).

The rate of endometriosis-related hospitalisation varied by the region of birth (Figure 6). Rates were highest among patients born in the Americas, and lowest among patients born in Southern and Eastern Europe.

Median age also varied with country of birth. The median age of Australian-born endometriosis patients was lower than all other regions.

Figure 6: Endometriosis-related hospitalisations, by region of birth, 2021–22

Alt text: This interactive bar chart shows endometriosis-related hospitalisations by region of birth in 2021–22. Measures included are number of hospitalisations, hospitalisations per 100,000 population (crude rate) and median age. Australia had the highest number of hospitalisations at 29,980. The Americas had the highest crude rate of hospitalisations at 395 per 100,000 population. Australia had the youngest median age out of all regions at age 33.

Select measure
Hospitalisations per 100,000 population (crude rate)

Select diagnosis scope
◉ Any diagnosis of endometriosis
◯ Principal diagnosis of endometriosis

Region

Notes
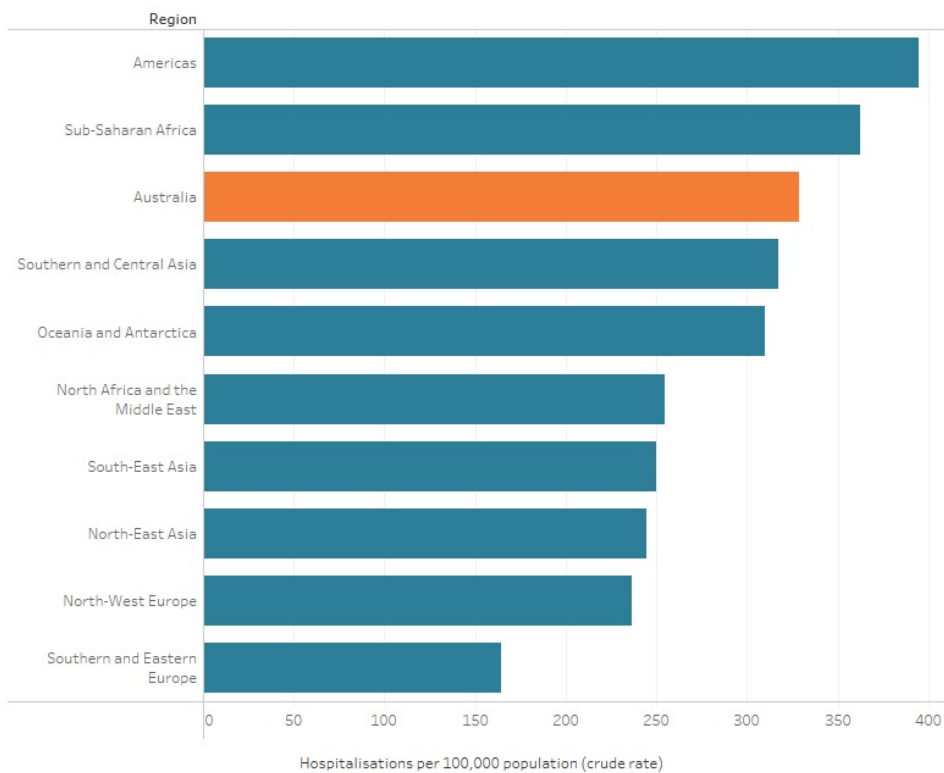
Source: AIHW National Hospital Morbidity Database (NHMD).
https://www.aihw.gov.au

Funding source

Most endometriosis-related hospitalisations were partly or fully funded by private health insurance (58%). A further 28% were for public patients, while 9.6% were for self-funded patients. Over two-thirds (68%) of endometriosis-related hospitalisations took place in a private hospital.

Compared with all female hospitalisations in 2021–22, endometriosis-related hospitalisations were more likely to be partly or fully funded by private health insurance, self-funded, or occur in a private hospital (Table 1a and Table 1b). As of June 2022, 16% of females aged 15–44 had private health insurance coverage for hospital treatment (APRA 2023).

Table 1a: Endometriosis hospitalisations by funding source, 2021–22

Funding source	Endometriosis hospitalisations, ages 15-44 (%)	Endometriosis hospitalisations, all ages (%)	All female hospitalisations, ages 15-44 (%)	All female hospitalisations, all ages (%)
Private health insurance (partly or fully funded)	57.4	58.3	32.2	40.4
Health service budget	27.6	27.8	55.5	49.5
Self-funded	10.6	9.6	7.3	4.3
Other	4.3	4.3	4.9	5.9
Total	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW National Hospital Morbidity Database (NHMD).

Table 1b: Endometriosis hospitalisations by hospital sector, 2021–22

	Endometriosis hospitalisations, ages 15-44 (%)	Endometriosis hospitalisations, all ages (%)	All female hospitalisations, ages 15-44 (%)	All female hospitalisations, all ages (%)
Public hospital	31.5	31.6	62.5	57.7

Private hospital	68.5	68.4	37.5	42.3
Total	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW National Hospital Morbidity Database (NHMD).

Elective surgery waiting times for publicly-funded procedures may influence an individual's decision to opt for privately-funded treatment. See _Procedures_ for more information on common procedures for endometriosis and elective surgery waiting times.

Length of stay

Most endometriosis-related hospitalisations lasted 2 days or less, with 43% being same-day hospitalisations (Table 2). The average length of stay was slightly shorter for hospitalisations with endometriosis as a principal diagnosis, compared with that for all endometriosis-related hospitalisations.

The average length of stay for endometriosis-related hospitalisations was shorter than that for all female hospitalisations:

- 1.6 days compared with 2.7 days for all female hospitalisations
- 2.1 days compared with 5.4 days for all female hospitalisations excluding same-day hospitalisations.

Table 2: Length of stay for endometriosis-related hospitalisations, 2021–22

	Hospitalisations with endometriosis as the principal diagnosis	All endometriosis-related hospitalisations
Length of stay	%	%
Same day	42.4	43.0
1–2 days	47.7	44.5
3–4 days	7.6	9.4
5-6 days	1.5	1.9
7+ days	0.8	1.3
Total	**100.0**	**100.0**
	Mean (days)	Mean (days)
Length of stay	1.4	1.6
Length of stay excluding same-day hospitalisations	1.8	2.1

Source: AIHW National Hospital Morbidity Database (NHMD).

Procedures

In 2021–22, 94% of endometriosis-related hospitalisations involved at least 1 procedure (Table 3). _Laparoscopic excision of lesion of pelvic cavity_ and _diagnostic hysteroscopy_ were the most common procedures, each occurring in 42% of endometriosis-related hospitalisations.

Table 3: Most common procedures undertaken during endometriosis-related hospitalisations, 2021–22

Rank	Procedure code	Procedure name	Description	Per cent of hospitalisations
1	35637-10	Laparoscopic excision of lesion of pelvic cavity	Removal of lesions by cutting	42.5
2	35630-00	Diagnostic hysteroscopy	Examination of the inside of the uterus	41.8
3	35640-00	Dilation and curettage of uterus [D&C]	In which the lining of the uterus is scraped away	37.9
4	30393-00	Laparoscopic division of abdominal adhesions	In which adhesions are cut and divided	23.6
5	35703-00	Test for tubal patency	Assessment of whether fallopian tubes are blocked, used in investigating infertility	18.6

6	35637-02	Laparoscopic diathermy of lesion of pelvic cavity	Removal of lesions by burning	17.0
7	35503-00	Insertion of intrauterine device [IUD]	Insertion of a contraceptive device, which is also used in the treatment of endometriosis	15.5
8	36812-00	Cystoscopy	Examination of the inside of the bladder	13.4
9	35638-10	Laparoscopic salpingectomy, bilateral	Removal of both fallopian tubes	12.0
10	35653-07	Laparoscopic total abdominal hysterectomy	Removal of the uterus	11.5

Notes:

1. Procedures were counted only once if the same procedure was conducted more than once in a hospitalisation.
2. Procedures for cerebral anaesthesia (ACHI block code 1910) and were not included in this analysis—these are companion procedures for many other procedures.
3. 'Diagnostic hysteroscopy' is the name of a procedure in the ACHI and does not imply that this procedure is being used to diagnose endometriosis.

Source: AIHW National Hospital Morbidity Database (NHMD).

Waiting times for procedures

Individuals seeking publicly-funded surgery for endometriosis will be added to the public hospital waiting list. It is not possible to identify waiting times specifically for the treatment of endometriosis, however some information is available on procedures which commonly occur in endometriosis-related hospitalisations.

Elective surgery waiting times

Elective surgery is planned surgery that can be booked in advance as a result of a specialist clinical assessment. Elective surgery is considered medically necessary, and may be required urgently, but is not conducted as a result of an emergency presentation. The National Elective Surgery Waiting Times Database captures data from procedures performed in public hospitals following a patient's placement on a public hospital waiting list. The data on elective surgery waiting times is captured after the procedure is performed, so does not reflect the status of people currently waiting for surgery.

Some procedures for which waiting time information is available and may be used in the treatment of endometriosis include *cystoscopy*, *hysteroscopy, dilation and curettage* and *laparoscopy* (Table 4). It is important to note that these waiting times data include all sexes and are not limited to patients with a diagnosis of endometriosis.

According to the National Elective Surgery Waiting Times Database, in 2021–22

- Almost 52,000 *cystoscopy* (examination of the inside of the bladder) procedures were performed. Half of patients were admitted within 24 days, with 90% seen within 132 days.
- Just over 30,000 *hysteroscopy, dilation and curettage* procedures were performed. Half of patients had their procedure in less than a month (within 27 days), with 90% seen within 157 days.
- Almost 8,500 *laparoscopy* procedures were performed. Half of patients had their procedure in less than 3 months (within 78 days), with 90% seen within almost a year (354 days).

Table 4: Waiting times of selected elective surgeries, all hospitalisations, 2021–22

Procedure	Number of procedures performed	Median waiting time (days)	Time waited at the 90th percentile (days)	Percentage of people who waited more than 365 days
Cystoscopy	51,749	24	132	1.6
Hysteroscopy, dilation and curettage	30,021	27	157	1.6
Laparoscopy	8,472	78	354	7.7

Note: Procedure names are based on the intended procedure code, see Elective surgery waiting list episode – intended procedure, code NNN.

Source: AIHW National Elective Surgery Waiting Times Database.

Co-occurring diagnoses

In 2021–22, 80% of hospitalisations with a principal diagnosis of endometriosis had one or more additional diagnoses reported. Of these hospitalisations, 41% included another endometriosis diagnosis as an additional diagnosis.

Excluding endometriosis-related additional diagnoses, the most common additional diagnoses were *female pelvic peritoneal adhesions* (16% of hospitalisations) and *peritoneal adhesions* outside of the pelvis, such as on the abdominal wall or intestine (12%). *Insertion of contraceptive device* was recorded in 9.2% of hospitalisations.

For hospitalisations with endometriosis as an additional diagnosis, 21% had a principal diagnosis of *pelvic and perineal pain*. Diagnoses related to menstruation, infertility or in vitro fertilisation were also common.

A summary of the most common diagnoses co-occurring with endometriosis is included in the data tables.

Endometriosis and other chronic conditions

People with endometriosis may also experience other chronic conditions. The National Action Plan for Endometriosis supports the consideration of a number of related conditions, such as polycystic ovarian syndrome, adenomyosis, pelvic inflammatory disease and chronic pelvic and period pain (Department of Health 2018). Some of these conditions are commonly co-occurring diagnoses with endometriosis (Tables 5 & 6).

Pelvic and perineal pain

Pelvic and perineal pain is a commonly reported symptom of endometriosis. In 2021–22, 29% of hospitalisations for pelvic and perineal pain had an additional diagnosis of endometriosis. In comparison, 2.5% of hospitalisations where endometriosis was the principal diagnosis had pelvic and perineal pain as an additional diagnosis.

Polycystic Ovarian Syndrome

Polycystic Ovarian Syndrome (PCOS) is a hormonal condition, with common symptoms including irregular menstrual cycles, excess hair growth (hirsutism), acne, weight gain, infertility, as well as an increased risk of anxiety and depression (Better Health Channel, 2019). PCOS and endometriosis are conditions that affect the female reproductive system, and it is possible for both conditions to occur at the same time (Holoch et al. 2014). In 2021–22, 12% of hospitalisations for PCOS had an additional diagnosis of endometriosis. In the same year, less than 1.0% of hospitalisations for endometriosis had an additional diagnosis of PCOS.

Uterine fibroids

Uterine fibroids are noncancerous growths that can occur inside the uterus, as well as the fallopian tubes, cervix or tissues near the uterus (Health Direct 2021). Some common symptoms of uterine fibroids are heavy or prolonged periods, bleeding between periods, dysmenorrhoea (painful periods) and pain in the pelvic area. In some cases, uterine fibroids can also affect fertility (RANZCOG 2018). In 2021–22, 15% of hospitalisations for uterine fibroids had an additional diagnosis of endometriosis. In the same year, 4.6% of hospitalisations where endometriosis was the principal diagnosis also had a diagnosis of uterine fibroids.

Female pelvic inflammatory disease

Pelvic Inflammatory Disease (PID) is an infection or inflammation of organs in the female reproductive tract, including the uterus, vagina and fallopian tubes (Better Health Channel 2022). In 2021–22, 3.0% of hospitalisations for PID had an additional diagnosis of endometriosis. Less than 1.0% of hospitalisations where endometriosis was the principal diagnosis had an additional diagnosis of PID.

Adenomyosis

Adenomyosis is a condition where cells similar to the lining of the uterus also grow in the muscle wall of the uterus (Jean Hailes for Women's Health 2023). Like endometriosis, adenomyosis is characterised by the presence of endometrial-like tissue, and can cause similar symptoms related to pain, bleeding and infertility. In the ICD-10-AM, adenomyosis is grouped with endometriosis of the uterus, meaning it is not possible to know how many hospitalisations included a specific diagnosis of adenomyosis.

Table 5: Hospitalisations for selected endometriosis-related conditions (principal diagnosis), 2021–22

Principal diagnosis	Proportion of hospitalisations with endometriosis as an additional diagnosis (%)	Total hospitalisations
Pelvic and perineal pain	29.3	13,913
Uterine fibroids	15.1	8,830
Polycystic Ovarian Syndrome (PCOS)	12.0	299
Female pelvic inflammatory disease	3.0	1,738
Uterine/endometrial polyps	2.5	10,418
Chronic pain	0.2	1,264
IBS	0.1	3,299

Note: For corresponding ICD-10-AM codes see Technical notes.

Source: AIHW National Hospital Morbidity Database (NHMD).

Table 6: Hospitalisations with selected endometriosis-related conditions (additional diagnosis), 2021–22

Additional diagnosis	Proportion of endometriosis hospitalisations with this additional diagnosis (%)
Uterine fibroids	4.6
Chronic pain	3.1
Pelvic and perineal pain	2.5
PCOS	0.4
Female pelvic inflammatory disease	0.2

Notes:

1. For corresponding ICD-10-AM codes see Technical notes.
2. No hospitalisations with an endometriosis principal diagnosis had an additional diagnosis of IBS or Uterine/endometrial polyps.

Source: AIHW National Hospital Morbidity Database (NHMD).

References

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Treatment & management

Australia's hospital system has played a significant role in managing and treating people infected with COVID-19. The COVID-19 pandemic also had a profound impact on hospital activity more broadly. The range of social, economic, business and travel restrictions, including restrictions on some hospital services, and associated measures in other healthcare services to support social distancing in Australia resulted in an overall decrease of 2.8% in hospital activity between 2018–19 and 2019–20 (AIHW 2022). Hospitalisations then increased by 6.3% from 2019–20 to 2020–21 as restrictions on hospital activity eased.

The COVID-19 pandemic and associated health service restrictions had a considerable impact on endometriosis-related hospitalisations.

As part of the Australian Government's response to the COVID-19 pandemic, all non-urgent elective surgery was suspended for 1 month from 26 March to 27 April 2020. Many of the procedures used in the diagnosis and treatment of endometriosis, such as laparoscopy and hysteroscopy, are classified as elective surgery category 3 'non-urgent'.

The effect of this suspension is seen in the monthly data for endometriosis-related hospitalisations, with a considerable drop in hospitalisations in April 2020.

Patterns in the following months vary by jurisdiction, mirroring the differences in restrictions and public health measures seen in each state and territory. Nationally, endometriosis-related hospitalisations peaked in July 2020, and comparatively higher volumes were seen for the end of the year and the first half of 2021. This likely reflects programs implemented by jurisdictions to fast-track elective surgeries and provide increased funding for surgeries which were delayed because of the earlier restrictions on elective surgery.

In 2020, endometriosis-related hospitalisations followed a different pattern in Victoria from the rest of the country, with a second drop in August reflecting the state's second wave.

Prior to COVID-19, endometriosis-related hospitalisations varied month-to-month with lowest numbers seen in December and January (Figure 7). This aligns with general trends of reduced elective surgery around the holiday period.

Figure 7: Monthly variation of endometriosis-related hospitalisations by state or territory of hospital, 2018-2021

Alt text: This interactive line chart shows the number of endometriosis-related hospitalisations by month and state and territory from 2018 to 2021. In Australia, hospitalisations of any diagnosis of endometriosis peaked in July 2020 at 4,104 and were lowest in April 2020 at 1,139. Similar patterns were seen for a principal diagnosis of endometriosis as with any diagnosis of endometriosis.

Visualisation not available for printing

References

AIHW (Australian Institute of Health and Welfare) (2022) *Admitted patients*, AIHW website, accessed 23 October 2022.

Treatment & management

Page highlights

- There were more than 3,600 endometriosis-related emergency department (ED) presentations in 2021–22. This represents around 28 presentations per 100,000 females.
- The rate of endometriosis-related ED presentations was highest in the 20–24 age group.
- The number and rate of endometriosis-related ED presentations has fluctuated between 2018–19 and 2021–22, peaking at 3,700 presentations in 2020–21.
- 72% of endometriosis ED presentations were triaged as needing to be seen within 30 minutes or less.

Almost all (95%) endometriosis-related ED presentations had endometriosis listed as the principal diagnosis.

Most endometriosis-related ED presentations were among females aged 15–44 (Figure 8). The rate of endometriosis-related ED presentations was highest in the 20–24 age group.

Around 71% of endometriosis-related ED presentations in 2021–22 ended with the patient leaving the hospital without being admitted or referred to another hospital. For 27% of the endometriosis-related presentations the patient was admitted to the same hospital for further care.

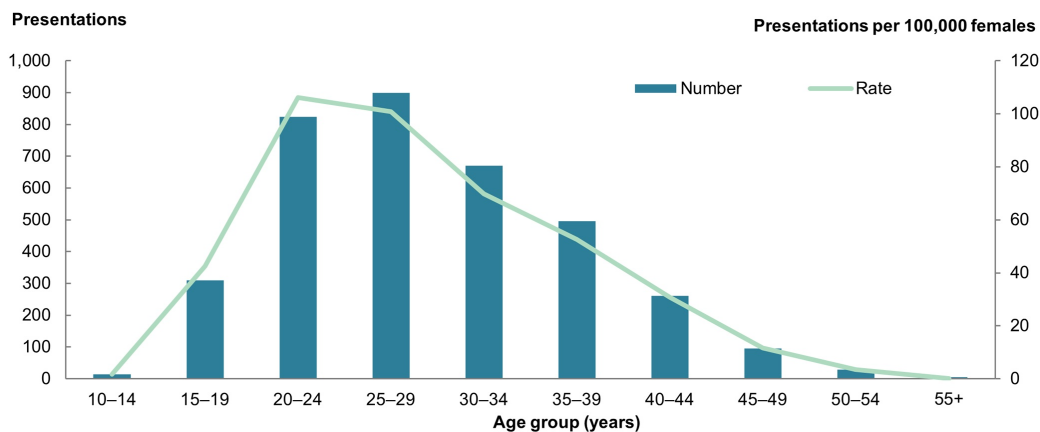**Figure 8: Number and rate of endometriosis-related emergency department presentations, by age group, 2021–22**

Chart: AIHW. Source: AIHW National Non-admitted Patient Emergency Department Care (NNAPEDC).

What is an endometriosis-related emergency department presentation?

Emergency department data presented here are based on non-admitted patient episodes of care from the National Non-admitted Patient Emergency Department Care Database (NNAPEDCD), including multiple events experienced by the same individual in a given time frame.

- An **emergency department** provides triage, assessment, care and/or treatment for patients suffering from medical conditions and/or injury.
- **Endometriosis-related emergency department presentations** are emergency department presentations with a principal and/ or additional diagnosis of endometriosis.
- **Triage** is the process by which a patient is briefly assessed to determine the urgency of their problem and priority for emergency care.

The health classification used for emergency department presentation diagnosis reporting in Australia is the Emergency Department ICD-10-AM Principal Diagnosis Short List.

For further information on the NNAPEDCD and the methods used in this report, see the Technical notes.

Triage category

Triage category is used to indicate the level of urgency of a patient's need for care. Of all endometriosis-related ED presentations in 2021–22:

- 9.5% were categorised as 'resuscitation' (requiring immediate care) or 'emergency' (within 10 minutes)
- 63% as 'urgent' (within 30 minutes)
- 26% as 'semi-urgent' (within 60 minutes)
- 1.4% as 'non-urgent' (within 120 minutes).

Trends over time

The number and rate of ED presentations due to endometriosis (where endometriosis was the principal diagnosis) has fluctuated in recent years. Between 2018–19 and 2021–22 (the period for which reliable diagnosis information is available nationally), the highest number of ED presentations due to endometriosis was in 2020–21 with 3,700 presentations (Figure 9). This is a similar pattern to that seen among all female ED presentations in this period, likely influenced by the COVID-19 pandemic. As additional years of data become available in future, it will be possible to gain a better understanding of trends in endometriosis ED presentations.

An individual may present to the ED with symptoms of endometriosis before they have received a diagnosis. In these cases, diagnoses related to pain, abnormal bleeding or menstrual issues are likely to be recorded. Figure 9 displays ED presentations for several diagnoses which may be related to endometriosis.

Figure 9: Emergency Department presentations for endometriosis and other selected diagnoses (principal diagnosis), 2018-19 to 2021-22

Alt text: This interactive line and bar chart shows the number and rate of emergency department presentations due to endometriosis and other selected diagnoses, including abnormal vaginal or uterine bleeding, acute pain in abdomen, pain in upper abdomen, pain in lower abdomen and other pain in abdomen. Other pain in abdomen was the diagnosis with the highest number and rate of ED presentations in all years.
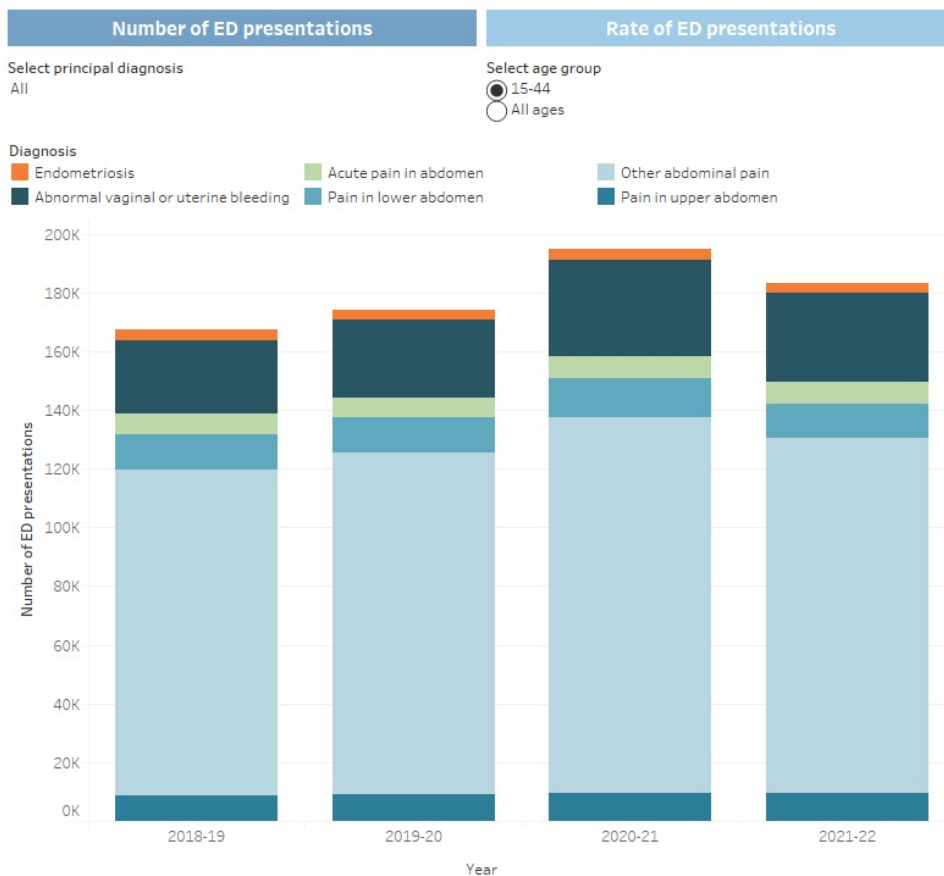
Note: Rates were calculated using the December estimated resident population for females.
Source: National Non-admitted Patient Emergency Department Care (NNAPEDC) Database.
https://www.aihw.gov.au/

Impact

Endometriosis can have a substantial impact on individuals. Symptoms can be debilitating and may affect quality of life, fertility, and lead to reduced participation in school, work and social activities.

This section presents 2 key measures of impact:

- estimates of the burden of disease of endometriosis
- estimates of the economic burden of endometriosis.

Impact

> **Page highlights**
>
> - There were 8,213 years lived with disability (YLD) due to endometriosis in 2023.
> - The disease burden due to endometriosis is highest among females aged 30–34 with a rate of 1.71 YLD per 1,000 females.
> - The YLD rate for endometriosis has increased by 40% between 2003 and 2023, after adjusting for differences in age structure over time (0.48 and 0.67 per 1,000 population, respectively).
> - Endometriosis is the third leading cause of non-fatal disease burden among females due to reproductive and maternal conditions, after genital prolapse and polycystic ovarian syndrome.

Burden of disease measures the gap between the ideal of living to old age in good health, and the current situation where healthy life is shortened or lost by illness, injury, disability and death. It combines health loss from living with illness and injury (non-fatal burden, or years lived with disability, or YLD) and dying prematurely (fatal burden, or years of life lost, or YLL) to estimate total health loss (total burden, or disability-adjusted life years, or DALY). For endometriosis, there is no burden due to dying prematurely, so only non-fatal burden (YLD) is reported. One YLD is one year of 'healthy life' lost due to illness.

What is the burden of disease due to endometriosis?

The Australian Burden of Disease Study 2023 found that there were 8,213 YLD from endometriosis in Australia, a rate of 0.61 per 1,000 females (AIHW 2023). The disease burden due to endometriosis:

- represents 13% of the non-fatal burden among females due to reproductive and maternal conditions, the third highest burden in this condition group (Figure 10)
- represents 0.51% of the non-fatal burden among females in Australia
- is highest among females aged 30–34 with 1,676 YLD, equivalent to 1.71 YLD per 1,000 females (Figure 10)
- results in endometriosis being the 15th leading cause of non-fatal burden among females aged 30–34.

After adjusting for differences in age structure over time, the YLD rate for endometriosis has increased by 40% between 2003 and 2023. This change may be driven by changes in disease prevalence, community awareness or diagnosis.

## Figure 10: Non-fatal burden of disease due to endometriosis, 2003-2023

Alt text: The first chart in this interactive visualisation shows the total YLD and YLD crude rate per 1,000 population due to endometriosis by age group and year. Across all years, the YLD and YLD crude rate increased with age, reaching a peak between 30–39 years, then decreasing. The second chart in this interactive visualisation shows the proportion of non-fatal burden attributed to reproductive and maternal conditions. In 2022, genital prolapse had the highest proportion of non-fatal burden, followed by polycystic ovarian syndrome, then endometriosis.

In 2023, there were
8,213 YLD in Females
from Endometriosis, equivalent to **0.67 per 1,000 population** (age-standardised rate) and **0.5%** of the non-fatal burden in Australia.
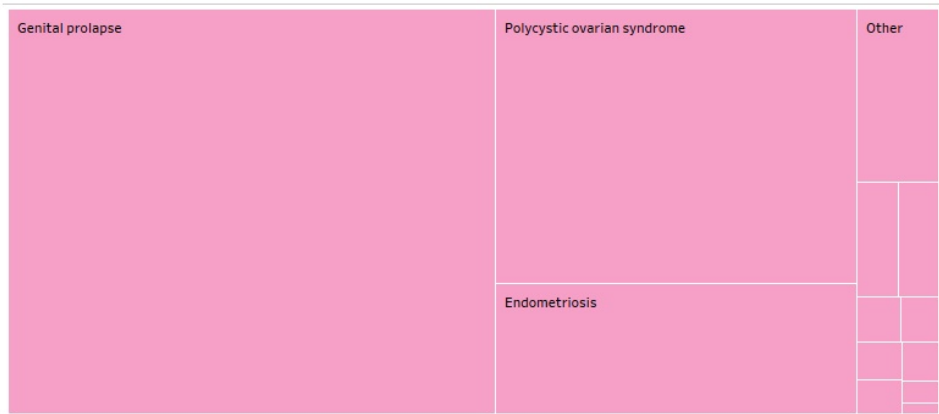
Note: Diseases displaying a rate of 0.00 per 1,000 population refer to a rate <0.005 per 1,000 population.

Endometriosis YLD in Females by age, 2023

Legend:
- Crude rate (per 1,000 population)
- Number
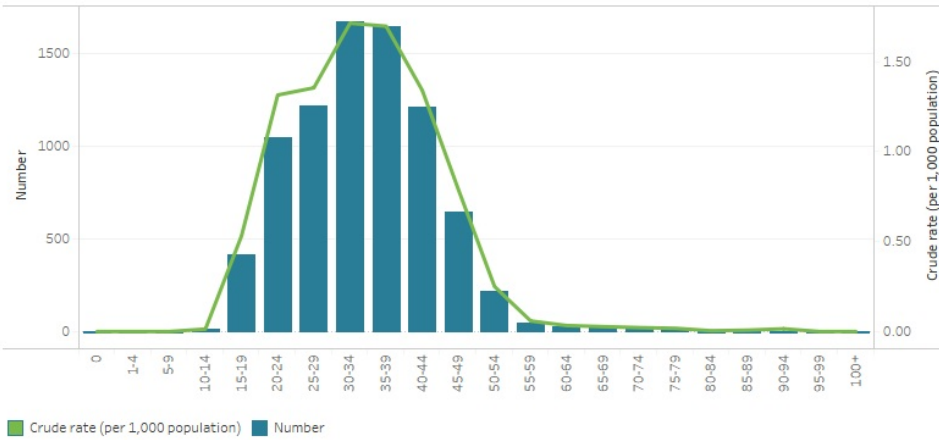
YLD in Females by disease group, 2023

- Reproductive and maternal conditions

Genital prolapse | Polycystic ovarian syndrome | Other
Endometriosis

Notes: Rates were age-standardised to the 2001 Australian Standard Population and are expressed as per 1,000 population. Refer to the technical notes for more information on data sources and methods used in the Study.
Source: AIHW Australian Burden of Disease Database.
https://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2023) *Australian Burden of Disease Study 2023*, AIHW website, accessed 14 December 2023.

Impact

Page highlights

- An estimated $247.2 million was spent on endometriosis in the Australian health system in 2020–21.
- Around 86% of endometriosis expenditure was attributed to hospitals (including public hospital admitted patient, outpatient and emergency department services and private hospital services).
- Females aged 35–39 years had the highest expenditure amongst all age groups, accounting for around 20% of total endometriosis expenditure.

Health system expenditure

The Australian Disease Expenditure Study showed that in 2020–21, an estimated $247.2 million was spent on endometriosis in the Australian health system (AIHW 2023b). This represents less than 1% of spending attributable to specific disease groups.

This expenditure consisted of:

- $212.4 million for hospitals (including public hospital admitted patient, outpatient and emergency department services and private hospital services)
- $21.1 million for referred medical services (including pathology, medical imaging and specialist services)
- $13.6 million for primary health care (including General Practitioner services and Pharmaceutical Benefits Scheme expenditure).

Around 83% of total expenditure on endometriosis was attributed to females of reproductive age (aged 15–44 years). Females aged 35–39 years had the highest expenditure amongst all age groups, accounting for around 20% of total endometriosis expenditure.

These estimates include payments from all sources of funds, such as the Australian and State and Territory Governments, Private Health Insurance, and out of pocket payments by patients, where spending can be attributed to the treatment of endometriosis. It is likely to underestimate spending where data are lacking on endometriosis-related services, such as primary care services and medicines.

Cost of endometriosis

The cost of disease is not just financial: being unwell has other effects on quality of life, affecting people's ability to work or do the activities they enjoy. The spending estimates do not include direct costs from outside of the health care sector or estimates of the indirect costs due to illness. The total economic burden of endometriosis has been estimated at between $7.4 billion and $9.7 billion per year (Armour et al. 2019; Ernst & Young 2019)

One Australian study estimated the cost of endometriosis was $30,900 per person with the condition in 2017 (Armour et al. 2019). This consisted of:

- $25,800 for productivity costs
- $3,900 for total health costs
- $1,100 for carer costs.

Lost productivity due to endometriosis accounted for 84% of these costs. Costs increased with pain severity, with costs for people reporting severe pain 6 times as high as those reporting minimal pain.

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Data gaps and opportunities

Comprehensive, accurate and timely data are necessary for effective population health monitoring of endometriosis. The National Action Plan for endometriosis calls for improved data capture, use and linkage to improve understanding of the current state, impact, and burden of endometriosis in Australia (Department of Health 2018).

Gaps and limitations

The analysis in this report predominantly describes hospital and emergency department care for endometriosis, which likely reflects management of more severe symptoms. Information on the use of primary care, specialist care or pharmaceutical treatment would provide a more complete picture of endometriosis in Australia, but is limited by the absence of suitable data sources. Current gaps on the health of people living with endometriosis include:

- national, comparable and reportable data on primary health care activity and outcomes
- outcomes of endometriosis-related hospitalisations and emergency department presentations
- emergency department presentations due to endometriosis symptoms prior to receiving a diagnosis
- treatment pathways for people with endometriosis, including multiple hospitalisations or emergency department presentations
- information on some population groups, including First Nations people, people with disability, culturally and linguistically diverse populations, refugees and LGBTIQA+ populations.

Data linkage opportunities

Where data are available, analysis can be limited by the inability to identify endometriosis as the purpose of treatment. Linked data presents an opportunity for improved understanding of the experiences and treatment patterns for people with endometriosis. Examples of linked data sources which could be explored for endometriosis include:

- <u>National Integrated Health System Information</u>: NIHSI is a major national linked health data asset comprising data on admitted patient care services, emergency department services, outpatient services, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Repatriation Pharmaceutical Benefits Scheme (RPBS), Residential Aged Care services, National Death Index (NDI) and the Australian Immunisation Register (AIR). Analysis could describe patient pathways and health service use in the years preceding and succeeding a diagnosis of endometriosis. This analysis could also explore the use of MBS services and the medicines provided under the PBS for the treatment of endometriosis.
- <u>Multi-Agency Data Integration Project</u>: MADIP is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time. Analysis could explore the impact of endometriosis beyond a person's health, such as reduced participation in school, work and sporting activities.

Investment in endometriosis research

The National Health and Medical Research Council has expended $18.9 million towards research relevant to endometriosis between 2000 and 2022.

From its inception in 2015 to 31 May 2023, the Medical Research Future Fund has invested $19.11 million in 11 grants with a focus on endometriosis research. Examples include:

- $3.93 million to the University of Melbourne for improving diagnosis and treatment of endometriosis
- $1.94 million to the University of New South Wales for The Australian Endometriosis Clinicians Collaborative (AECC)
- $1.47 million to Deakin University for CoDeEndo: Co-Designing, Evaluating, and Implementing Supportive Care for Endometriosis.

References

Department of Health (2018a) *National Action Plan for Endometriosis*, Department of Health, Australian Government, accessed 15 July 2022.

Technical notes

On this page

The Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (ALSWH) is an ongoing large population-based prospective cohort study focusing on women's health. Detailed information on the study methods have been published elsewhere (Brown et al. 1999; Dobson et al. 2015; Loxton et al. 2015; Rowlands et al. 2021).

The analysis presented in this report is based on data from 2 ALSWH cohorts –14,247 women born in 1973–78 and 17,015 women born in 1989–95.

Survey data

Data for endometriosis in the 1973–78 cohort were available from 8 surveys between 2000 and 2022. Data for endometriosis in the 1989–95 cohort were available from 5 surveys between 2013 and 2019. The specific ALSWH survey questions used to measure endometriosis are included in Table TN1. For both cohorts, the woman's survey response date was used as the date of her first record of endometriosis.

Administrative health data

Three additional sources of administrative health data were used to identify records of endometriosis. The codes used to identify endometriosis, and the time periods that data were available for each data source, are presented in Table TN2. Deterministic linkage of Medicare Benefits Schedule (MBS) records and Pharmaceutical Benefits Scheme (PBS) records for all ALSWH participants was conducted using their unique Medicare number. Hospital data, managed by individual states and territories, were extracted by the health data linkage units in these jurisdictions and linked to ALSWH data using probabilistic matching based on name, date of birth, address and address history.

For the 1973–78 cohort, hospital data were available for all 8 Australian states and territories, but the time periods for which data were available varied (see Table TN3). Hospital data for the 1989–95 cohort were not available for New South Wales or the Australian Capital Territory. Hospital data for all other jurisdictions covered most of the ALSWH survey period for this cohort (2012–2018).

For the 1973–78 cohort, 13,501 women (95%) consented to the linkage of survey data with their administrative health records. For the 1989–95 cohort, 16,972 (almost 100%) consented to the linkage of survey data with their administrative health records.

Statistical analysis

The overall prevalence of endometriosis for each cohort was calculated by combining survey data and administrative health data. Women who completed the baseline survey and who were successfully linked with MBS, PBS or admitted patient hospital data were used to calculate prevalence.

The cumulative incidence estimates by age were derived using the Kaplan-Meier method; instead of the traditional method of using time to failure, age at endometriosis diagnosis was used. The confidence intervals were derived using the variance estimate given by Greenwood's formula (Greenwood 1926).

For women born 1973–78, by age 44–49, a total of 1,914 cases of endometriosis were identified, corresponding to a prevalence of 14.2% (95% CI: 13.6–14.8%). Of these cases, 1,030 (7.6%, 95% CI: 7.2–8.1%) were confirmed by surgery, while 884 (6.6%, 95% CI: 6.1–7.0%) were categorized as clinically suspected.

For women born in 1989–95, by age 26–31,1,502 cases of endometriosis were diagnosed, corresponding to a prevalence of 8.8% (95% CI: 8.4–9.3%). Among these cases, 654 (3.8%, 95% CI: 3.5–4.1%) were confirmed by surgery, while 848 (5.0%, 95% CI: 4.7–5.3%) were categorized as clinically suspected.

Table TN1: ALSWH survey questions assessing endometriosis

Cohort	Initial survey question	Subsequent surveys

1973-78 cohort	Have you ever been told by a doctor that you have: endometriosis?[a] Response options: 'In the last 4 years' or 'More than 4 years ago'[b]	In the last 3 years, have you ever been diagnosed or treated for: endometriosis?
1989-95 cohort	Have you ever been diagnosed or treated for: endometriosis?	Have you ever been diagnosed or treated for: endometriosis? [c]

(a) Endometriosis first assessed at survey 2 for this cohort.

(b) Women's responses to both questions were combined to form 1 estimate.

(c) Question not assessed at survey 4 for this cohort.

Table TN2: Administrative health data sources used to identify endometriosis

Data source	Code(s)	Data available
MBS	35641	2000–August 2021
PBS	Goserelin (code: 01454M) Medroxyprogesterone 10 mg X 100 tablets (code: 02722G) Nafarelin (code: 02962X)	July 2002–August 2021
Admitted patient hospital data	International Statistical Classification of Diseases and Related Health Problems, 9th revision, clinical modification (ICD-9-CM) diagnostic codes 617.0–617.9 International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian modification (ICD-10-AM) diagnostic codes N80.0–N80.9	January 1970–March 2021[a]

(a) Refer to Table TN3 for specific dates.

Table TN3: Years of availability for hospital data, by state/territory and cohort

State/territory	Earliest record	Latest record	Data available for 1973-78 cohort	Data available for 1989-95 cohort
NSW	May 2001	March 2021	Yes	Yes
Vic	July 1993	December 2020	Yes	Yes
Qld	July 2007	June 2020	Yes	Yes
WA	January 1970	December 2017	Yes	Yes
SA[a]	January 2001	June 2020	Yes	Yes
Tas[a]	January 2007	December 2019	Yes	Yes
ACT[a]	July 2004	June 2020	Yes	Yes
NT[a]	July 2000	June 2019	Yes	Yes

(a) Public hospital data only.

National Hospital Morbidity Database

The National Hospital Morbidity Database (NHMD) is compiled from data supplied by the state and territory health authorities. It is a collection of electronic confidentialised summary records for hospitalisations (also known as separations or episodes of care) in public and private hospitals in Australia.

The NHMD is based on the Admitted Patient Care National Minimum Data Set (APC NMDS). It records information on admitted patient care in hospitals in Australia, and includes demographic, administrative and length-of-stay data, as well as data on the diagnoses of patients, the procedures they underwent in hospital and external causes of injury and poisoning.

The hospital separations data do not include episodes of non-admitted patient care given in outpatient clinics or emergency departments. Patients in these settings may be admitted later, with the care provided to them as admitted patients being included in the NHMD.

For more information on the NHMD, see National Hospitals Data Collection.

The following care types were excluded when undertaking the analysis: 7.3 (newborn – unqualified days only), 9 (organ procurement – posthumous) and 10 (hospital boarder).

A small number of hospitalisations (<10) were reported with a sex of 'male' or 'other'. To preserve confidentiality, data presented in this report have been restricted to hospitalisations with a sex of 'female' only.

Principal and additional diagnosis codes

Diagnoses were coded using the ICD-10-AM, with the edition applicable to the relevant data year as follows:

- Eleventh edition: 2021-22, 2020-21 and 2019-20
- Tenth edition: 2018-19 and 2017-18
- Ninth edition: 2015-16 and 2016-17
- Eighth edition: 2013-14 and 2014-15
- Seventh edition: 2011-12 and 2012-13.

Endometriosis-related hospitalisations were selected from the NHMD as follows:

- for all endometriosis-related hospitalisations, with a principal and/or additional diagnosis of endometriosis (ICD-10-AM codes N80.0–N80.9)
- for hospitalisations with a principal diagnosis of endometriosis, with a principal diagnosis of endometriosis (ICD-10-AM codes N80.0–N80.9)

The diagnosis code for endometriosis of the uterus (N80.0) is also used for the condition adenomyosis (a condition in which the cells that normally line the uterus are found in the muscular wall of the uterus). Although people who have adenomyosis often have endometriosis, endometriosis and adenomyosis are different conditions.

It is not possible to distinguish which of the records with the diagnosis 'endometriosis of the uterus' relate to adenomyosis and which relate to endometrial lesions on the surface of the uterus (that is, endometriosis). Records with the diagnosis 'endometriosis of the uterus' have been included in this report, which may result in an overestimate of endometriosis hospitalisations.

In _Endometriosis and other chronic conditions_, diagnoses were identified using the ICD-10-AM codes outlined in Table TN4.

Table TN4: Diagnosis codes for other chronic condition hospitalisations

Diagnosis code	Diagnosis
R10.2	Pelvic and perineal pain
D25	Uterine fibroids
E28.2	Polycystic Ovarian Syndrome (PCOS)
N73.9	Female pelvic inflammatory disease
N84.0	Uterine/endometrial polyps
R52.2	Chronic pain
K58	Irritable Bowel Syndrome (IBS)

National Non-admitted Patient Emergency Department Care Database

The National Non-admitted Patient Emergency Department Care Database (NNAPEDCD) is compiled from data supplied by the state and territory health authorities. It is a collection of electronic confidentialised summary records for presentations to public hospital emergency departments in Australia.

The NNAPEDCD is based on the Non-admitted Patient Emergency Department Care (NAPEDC). The NNAPEDCD provides information on the care provided (including waiting times for care) for non-admitted patients registered for care in public hospital emergency departments that have:

- purposely designed and equipped area with designated assessment, treatment, and resuscitation areas
- the ability to provide resuscitation, stabilisation, and initial management of all emergencies
- availability of medical staff in the hospital 24 hours a day
- designated emergency department nursing staff 24 hours per day 7 days per week, and a designated emergency department nursing unit manager.

Emergency departments (including 'accident and emergency' or 'urgent care centres') that do not meet the criteria above are not in scope for the NMDS, but data may have been provided for some of these by some states and territories.

A small number of emergency department presentations (<10) were reported with a sex of 'male' or 'other'. To preserve confidentiality, data presented in this report have been restricted to emergency department presentations with a sex of 'female' only.

Diagnoses were coded using Emergency Department ICD-10-AM Principal Diagnosis Short List, with the edition applicable to the relevant data year as follows:

- Eleventh edition: 2021-22, 2020-21 and 2019-20

- Tenth edition: 2018–19.

Prior to 2018–19, diagnoses were recorded using different classification systems between jurisdictions. In this report 2018–19 is the earliest year of data presented.

ED presentation for endometriosis, and other reported diagnoses, were identified as outlined in Table TN5.

Table TN5: Emergency Department analysis diagnosis codes

Reporting group	Diagnosis code	Diagnosis
Endometriosis	N80	Endometriosis
Abnormal vaginal or uterine bleeding	N93.9	Bleeding, vaginal or uterine, abnormal (except postmenopausal bleeding)
Acute pain in abdomen	R10.0	Pain in abdomen, acute
Pain in upper abdomen	R10.1	Pain in abdomen, upper
Pain in lower abdomen	R10.3	Pain in abdomen, lower (includes groin)
Other abdominal pain	R10.2	Pelvic and perineal pain
	R10.4	Other and unspecified abdominal pain

For more information on the NHMD, see _National Hospitals Data Collection_.

Australian Burden of Disease Study

The Australian Burden of Disease Study undertaken by the AIHW provides information on the burden of disease for the Australian population. Burden of disease analysis measures the impact of fatal burden (or years of life lost, YLL) and non-fatal burden (years lived with disability, YLD), with the sum of non-fatal and fatal burden equating the total burden (disability-adjusted life year, DALY).

The 2023 study builds on the AIHW's previous burden of disease studies and disease monitoring work. It provides Australian-specific estimates for over 200 diseases and injuries, grouped into 17 disease groups, for 2003, 2011, 2015 and 2018.

For more information, see _Australian Burden of Disease Study 2023_.

Australian Disease Expenditure Database

The AIHW Disease Expenditure Database provides a broad picture of the use of health system resources classified by disease groups and conditions.

It contains estimates of expenditure by the Australian Burden of Disease Study diseases and injuries, age group, and sex for admitted patient, emergency department and outpatient hospital services, out-of-hospital medical services, and prescription pharmaceuticals. Pharmaceutical benefit scheme expenditure includes over and under co-payment prescriptions.

It does not allocate all expenditure on health goods and services by disease – for example, neither administration expenditure nor capital expenditure can be meaningfully attributed to any particular condition due to their nature.

For more information, see _Disease expenditure in Australia 2020–21_.

Methods

Crude rates

The denominator for rate calculations was the estimated resident population (ERP) values for females as of 31 December for the given year (for example, crude rates for 2021–22 used the December 2021 population), unless otherwise noted.

Age-standardised rates

Age-standardisation is a method of removing the influence of age when comparing populations with different age structures – either different populations at one time or the same population at different times.

Direct age-standardisation was used in this report. The Australian estimated resident population as at 30 June 2001 has been used as the standard population.

First Nations hospitalisations

Rates were calculated using the female Aboriginal and Torres Strait Islander population estimates and projections (series B) based on the 2016 Census (ABS cat. no. 3238.0; ABS 2019), and non-Indigenous population estimates derived by subtracting the Indigenous population estimates from the female Australian Estimated Resident Population (ABS 2022). Financial year populations were calculated as the average of the 30 June population estimates for the two relevant calendar years.

Age-standardised rates are for ages 15 and over due to small numbers of endometriosis-related hospitalisations in younger age groups. Age-standardised rates calculated using 5-year age groups from 15 to 50+. Rates were standardised to the 2001 Australian standard population.

Hospitalisations by socioeconomic area

Socioeconomic areas are classified according to area-based quintiles using the ABS Index of Relative Socio-economic Disadvantage (IRSD). Further information is available on the ABS website.

The population denominator for rates of hospitalisation by socioeconomic area is the estimated resident population (ERP) values for females as of 30 June 2021.

Hospitalisations by remoteness area

Comparisons of regions in this report use the ABS Australian Statistical Geography Standard (ASGS) 2016 Remoteness Structure. In some instances, data for remoteness areas have been combined because of small sample sizes. Further information is available on the ABS website.

The population denominator for rates of hospitalisation by remoteness area is the estimated resident population (ERP) values for females as of 30 June 2021.

Hospitalisations by country of birth

Country of birth is reported based on the Standard Australian Classification of Countries (SACC), using the Major group classification presented as region of birth. Further information is available on the ABS website.

The population denominator for rates of hospitalisation by country of birth is the estimated resident population (ERP) values for females as of 30 June 2021.

Conversion of International dollars to Australian dollars

Estimated costs for endometriosis from Armour and others (2019) were converted from International dollars to 2017 Australian dollars using purchasing power parity (PPP) conversion factors where Int$1 = US$1, as per the original study methods. In 2017, the conversion factor was Int$1 = AUD$1.477553 (The World Bank 2023).

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Notes

Acknowledgements

Data

Related material

Resources