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Endometriosis in Australia: prevalence and hospitalisations

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Endometriosis is a chronic condition that can be painful, affect fertility and lead to reduced participation in school, work and sporting activities. The condition cost an estimated $7.4 billion in Australia in 2017–18, mostly through reduced quality of life and productivity losses (Ernst & Young 2019). This may be an underestimate, however, due to difficulties in diagnosing endometriosis and underdiagnosis.

What is endometriosis?

Endometriosis occurs when endometrial-like tissue, similar to the tissue normally found lining the uterus, is found in other parts of the body, such as the ovaries, fallopian tubes, peritoneum (the membrane lining the abdominal and pelvic cavities) and the outside of the uterus. These tissues are collectively known as endometriosis and, like the endometrial tissue lining the uterus, they respond to hormones released by the ovaries, causing bleeding. This leads to inflammation and scarring, which can cause painful 'adhesions' joining together pelvic organs which are normally separate.

The causes of endometriosis are unclear, but factors that seem to increase the risk of endometriosis include a family history of endometriosis and menstrual cycle factors such as early age at first period, short menstrual cycles, and heavy or long periods (Jean Hailes for Women's Health 2017b).

Some people with endometriosis experience no symptoms; others may experience pain, heavy menstrual bleeding, bleeding between periods, lethargy and reduced fertility, among other symptoms.

Around **1 in 9** women born in 1973–78 were **diagnosed** with endometriosis by age 40–44

There were around **34,200** endometriosis-related hospitalisations in 2016–17

Nearly **4 in 5** (79%) endometriosis-related hospitalisations in 2016–17 were among females **aged 15–44**

Around **15** of every 1,000 hospitalisations among females aged 15–44 in 2016–17 were endometriosis-related

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The recommended method of diagnosing endometriosis is via examination of specimens collected during laparoscopy (a type of keyhole surgery) (Dunselman et al. 2014). Based on the extent and location of the endometriosis, the condition is sometimes staged as minimal (stage I), mild (stage II), moderate (stage III) or severe (stage IV) (American Society for Reproductive Medicine 1997). However, the stages may not relate to the severity of symptoms experienced (Vercellini et al. 2007). Other systems for classifying endometriosis also exist (Johnson et al. 2017).

Diagnosis of endometriosis is often delayed, with an average of 7 years between onset of symptoms and diagnosis (Nnoaham et al. 2011). There is no known cure for endometriosis, although it can be managed with medical and/or surgical treatments, including the use of pain-killers, hormonal contraceptives or other hormonal treatments, and the removal of lesions via laparoscopy or laparotomy (abdominal surgery) (Dunselman et al. 2014). In some cases, the uterus may be removed (a hysterectomy); however symptoms can still reoccur.

In most (but not all) cases, the symptoms of endometriosis subside after menopause (Jean Hailes for Women's Health 2017a).

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 2018).

This report provides information about the prevalence of endometriosis in Australia, as well as endometriosis-related hospitalisations. Supplementary tables (tables S1–S12) can be viewed and downloaded at the AIHW website.

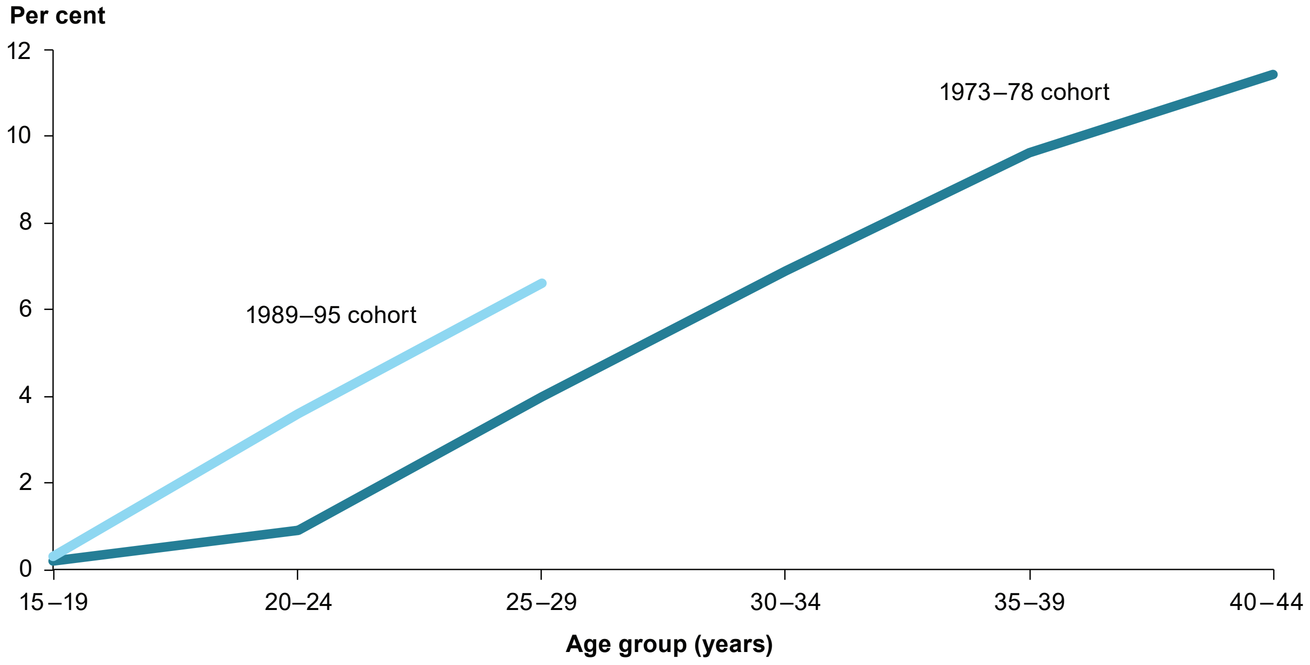
Around 1 in 9 women born in 1973–78 were diagnosed with endometriosis by age 40–44

The Australian Longitudinal Study on Women's Health (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 of endometriosis in these cohorts. The estimates were based on participant-reported diagnosis of, or treatment for, endometriosis; records of claims for an endometriosis-specific Medicare item; records of dispensed endometriosis-specific medications subsidised under the Pharmaceutical Benefits Scheme; and/or hospitalisations where a diagnosis of endometriosis was recorded. For further information on the data sources and methods used in this research, see the technical note in the supplementary tables.

Based on this research, around 1 in 9 (11%) women born in 1973–78 were estimated to have been diagnosed with endometriosis by age 40–44 (Figure 1; Table S1). Among women born in 1989–95, around 1 in 15 (6.6%) women were estimated to have been diagnosed with endometriosis by age 25–29 (Figure 1; Table S2).

A higher percentage of women born in 1989–95 had been diagnosed with endometriosis by age 25–29 compared with women born in 1973–78 (6.6% compared with 4.0%; Figure 1). This may reflect increased awareness of endometriosis among the general public and health professionals, leading to increased diagnosis and/or participant reporting of diagnosis or treatment among women born more recently.

Figure 1: Cumulative prevalence of endometriosis, by cohort and age



Source: Unpublished analysis of ALSWH linked data set; tables S1 and S2.

How does this study compare with others?

Estimates from other studies vary, and generally should not be compared directly with the estimates here as there are important differences between the studies. For example, there are differences in how endometriosis is reported (such as whether it is based on a self-reported or histologic diagnosis) and in the populations considered (such as differences in the range of ages included or whether studies were community based or of women presenting with gynaecological conditions).

One key difference between the estimates presented here and those from other studies (discussed in the text that follows) is the range of ages included. For example, the estimate here of 11% of women born in 1973–78 having been diagnosed with endometriosis by age 40–44 is based on women who have all reached the age of 40–44. This estimate is very likely to be higher than one that includes younger women, as women who are younger have had a shorter time over which to experience symptoms and/or be diagnosed.

Another Australian study

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.

Studies in other countries

In the United States, a study conducted from 1976 to 1984 estimated the prevalence of endometriosis as 'about 10%' among reproductive-age women; this estimate was based on 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).

In England, a study based on primary care records estimated the prevalence of endometriosis in girls and women aged over 16 as 1.44% (Pugsley & Ballard 2007).

There were around 34,200 endometriosis-related hospitalisations in 2016–17

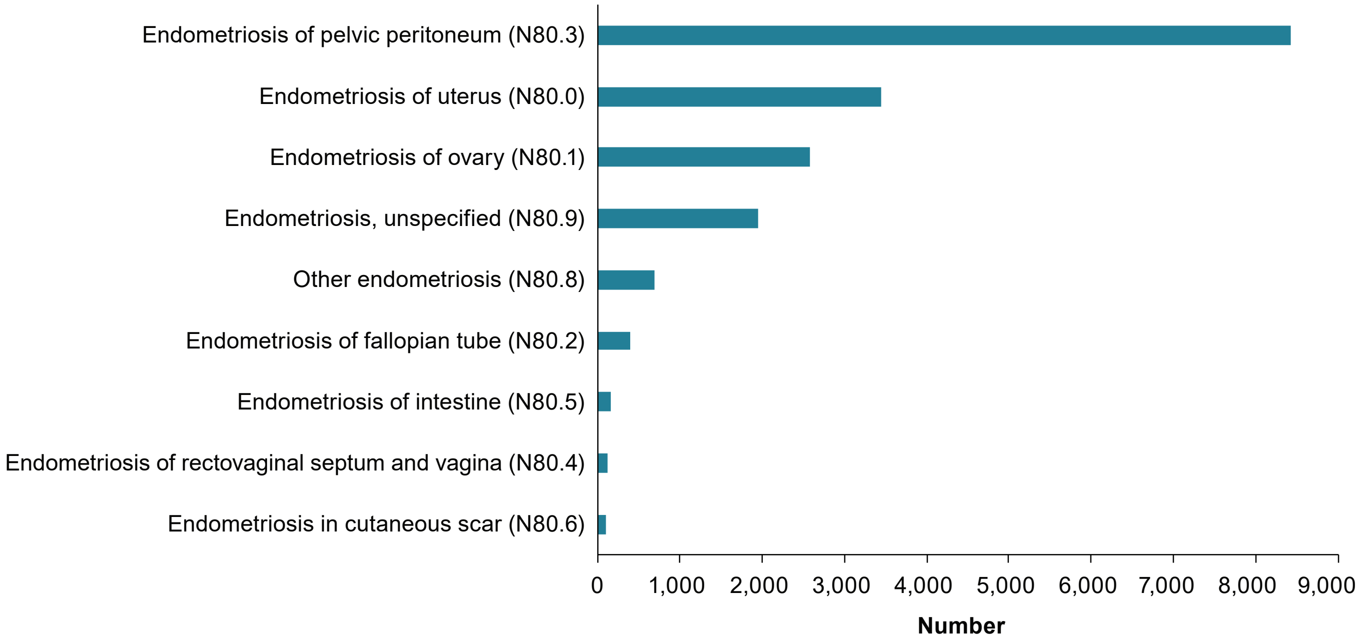
In 2016–17, there were around 34,200 endometriosis-related hospitalisations in Australia (Table S3). This was a rate of 281 hospitalisations per 100,000 females or around 6 of every 1,000 hospitalisations among females in 2016–17.

Of the endometriosis-related hospitalisations in 2016–17, around half (52%, or 146 per 100,000 females) had endometriosis as the principal diagnosis. The remainder had endometriosis as an additional diagnosis only (48%, or 135 per 100,000 females).

Of those hospitalisations with a principal diagnosis of endometriosis, the most common principal diagnosis was endometriosis of the pelvic peritoneum (47% of these hospitalisations), followed by endometriosis of the uterus (19%), endometriosis of the ovary (14%) and unspecified endometriosis (11%) (Figure 2; Table S4).

Almost 1 in 3 (31%) hospitalisations with a principal diagnosis of endometriosis also had 1 or more additional diagnoses of endometriosis.

Figure 2: Hospitalisations with a principal diagnosis of endometriosis, by 4th digit ICD-10-AM code, 2016–17



Note: Endometriosis of uterus (ICD-10-AM code N80.0) includes adenomyosis. Other endometriosis (N80.8) includes endometriosis of thorax. See the technical note in the supplementary tables for details.

Source: AIHW analysis of NHMD; Table S4.

Of those hospitalisations with endometriosis as an additional diagnosis only, the most common endometriosis diagnoses were endometriosis of the pelvic peritoneum (in 38% of these hospitalisations), endometriosis of the uterus (35%), unspecified endometriosis (17%), endometriosis of the ovary (14%) and other endometriosis (8.9%) (Table S5). Note that each hospitalisation could have more than 1 additional diagnosis of endometriosis.

How are hospitalisations reported?

The National Hospital Morbidity Database (NHMD) is a comprehensive data set that has records for all separations of admitted patients from essentially all public and private hospitals in Australia. A record is included for each separation, not for each patient, so patients who separated more than once in the year have more than 1 record in the NHMD.

An **admitted patient** is a patient who undergoes a hospital's formal admission process to receive treatment and/or care.

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**.

The **principal diagnosis** is the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care. The diagnosis can be a disease, condition, injury, poisoning, sign, symptom, abnormal finding, complaint, or other factor influencing health status.

Additional diagnoses are conditions or complaints either coexisting with the principal diagnosis or arising during the episode of admitted patient care. An additional diagnosis is reported if the condition affects patient management. As with the principal diagnosis, the diagnosis can be a disease, condition, injury, poisoning, sign, symptom, abnormal finding, complaint, or other factor influencing health status.

In the NHMD, diagnoses are coded using the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian modification (ICD-10-AM) (ACCD 2014).

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. As such, procedures encompass surgical procedures and non-surgical investigative and therapeutic procedures, such as X-rays. Patient support interventions that are neither investigative nor therapeutic (such as anaesthesia) are also included.

In the NHMD, procedures are coded using the Australian Classification of Health Interventions (ACHI) (ACCD 2015).

In this report, **endometriosis-related hospitalisations** are hospitalisations with a principal and/or additional diagnosis of endometriosis; that is, they are hospitalisations where endometriosis was either chiefly responsible for the hospitalisation or affected patient management. Data are also presented separately for **hospitalisations with endometriosis as the principal diagnosis** and for **hospitalisations with endometriosis as an additional diagnosis only** (that is, endometriosis was not also the principal diagnosis).

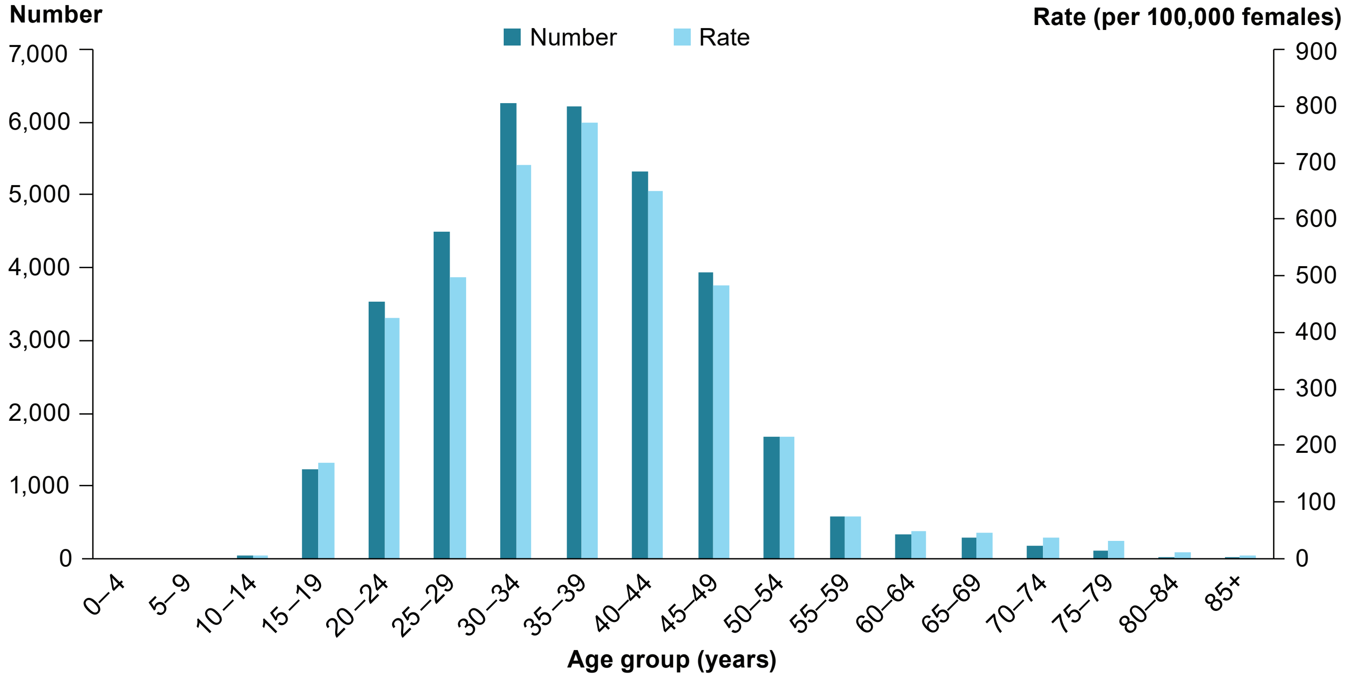
For further information on the NHMD and the methods used in this report, see the technical note in the supplementary tables.

Most endometriosis-related hospitalisations were among females of reproductive age

Nearly 4 in 5 (79%) endometriosis-related hospitalisations were among females aged 15–44, which are generally regarded as a woman's reproductive years (Table S3). This was a rate of 543 hospitalisations per 100,000 females aged 15–44 or around 15 of every 1,000 hospitalisations among females aged 15–44.

There were few hospitalisations among females aged under 15, with none among girls aged 0–9 (Figure 3; Table S3). The number and the rate of hospitalisations then rose with age to ages 30–34 and 35–39, respectively, before decreasing. There were relatively few hospitalisations among women aged 55 and over, potentially reflecting the decrease in endometriosis symptoms among most women after menopause.

Figure 3: Number and rate of endometriosis-related hospitalisations, by age, 2016–17



Source: AIHW analysis of NHMD; Table S3.

The greatest number of endometriosis-related hospitalisations was among women aged 30–34, with almost 6,300 hospitalisations. The highest rate of endometriosis-related hospitalisations was among women aged 35–39, at 770 per 100,000 women.

For hospitalisations with endometriosis as the principal diagnosis, the greatest number was among women aged 30–34 (nearly 3,500 hospitalisations) and the highest rate was among women aged 35–39 (410 per 100,000 women).

For hospitalisations with endometriosis as an additional diagnosis only, the greatest number and highest rate were both among women aged 35–39 (just over 2,900 hospitalisations; 360 hospitalisations per 100,000 women).

Rates of endometriosis-related hospitalisations varied by population group

The highest rate of endometriosis-related hospitalisations was among females living in *Inner regional* areas, followed by *Major cities*, *Outer regional* areas and *Remote and very remote* areas, after adjusting for differences in the age structure between remoteness areas (Figure 4; Table S6).

The rate of endometriosis-related hospitalisations was generally higher among females living in higher socioeconomic areas than among females living in lower socioeconomic areas, after adjusting for age.

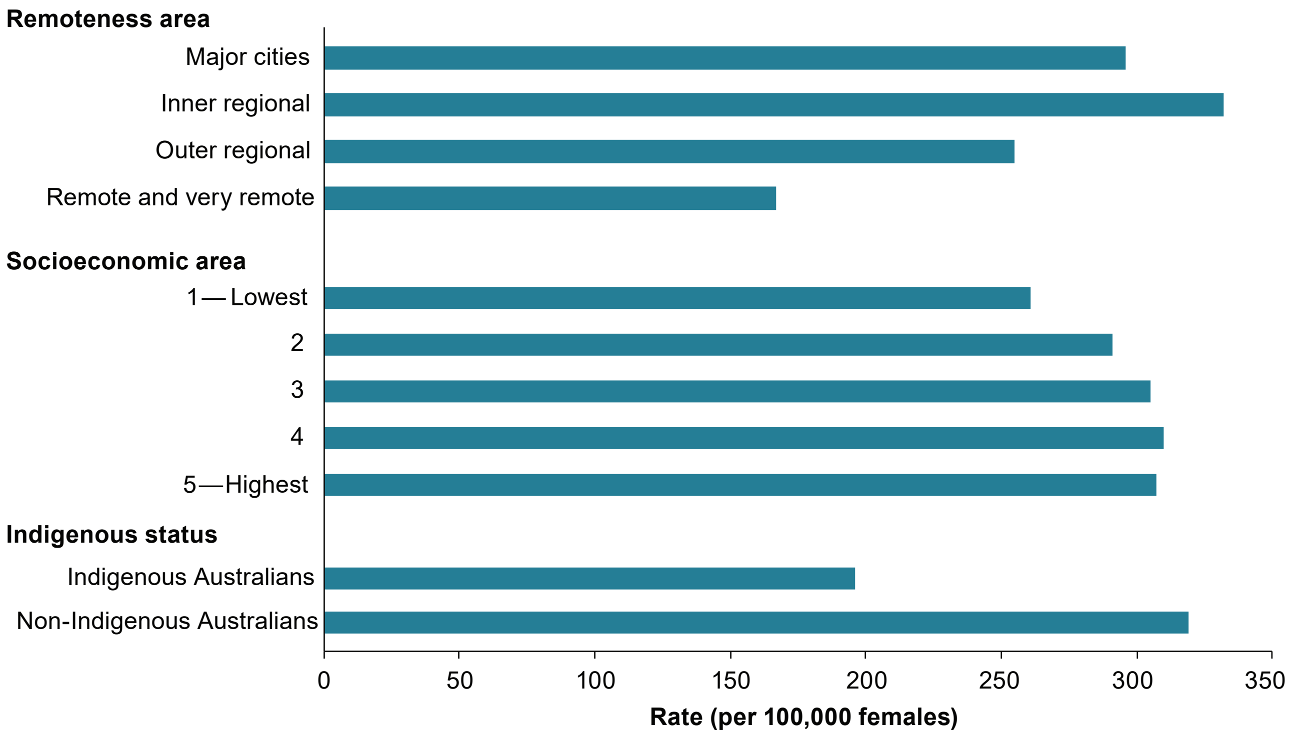
The rate of endometriosis-related hospitalisations among non-Indigenous Australians was 1.6 times as high as the rate among Indigenous Australians, after adjusting for age (319 hospitalisations per 100,000 females compared with 196 hospitalisations per 100,000 females).

The reasons for these differences are not known, but could reflect potential variations in access to health services or differences in health-seeking behaviour between population groups, rather than a difference in disease prevalence. For example, in another study, women living in small rural centres and other rural/remote areas in New South Wales were more likely to report only fair or poor access to a hospital than those living in urban areas or large rural centres (Young et al. 2000). However, in contrast to endometriosis-related hospitalisations, rates for all hospitalisations were higher for people living in *Remote* and *Very remote* areas than for those living in *Major cities* in 2016–17 (AIHW 2018).

For Indigenous Australians, there may be a range of barriers to health service access, including those related to:

- physical availability
- affordability
- appropriateness (through comprehensive and non-discriminatory services)
- acceptability (through culturally appropriate services) (Ware 2013).

Figure 4: Age-standardised rate of endometriosis-related hospitalisations, by population group, 2016–17



Source: AIHW analysis of NHMD; Table S6.

Around 1 in 13 endometriosis-related hospitalisations were self-funded

Most endometriosis-related hospitalisations were partly or fully funded by private health insurance (57%) (Table S7). A further 35% were for public patients, while 7.9% were for self-funded patients.

Endometriosis-related hospitalisations were more likely than all hospitalisations for females to be partly or fully funded by private health insurance (57% compared with 43%). They were also twice as likely to be self-funded as all hospitalisations for females (7.9% compared with 3.6%).

Endometriosis-related hospitalisations were also more likely than all hospitalisations for females to be in private hospitals (62% compared with 42%).

These differences are likely to be related to the generally greater numbers of endometriosis-related hospitalisations among females living in higher socioeconomic areas, as people living in higher socioeconomic areas are more likely to have private health insurance than those living in lower socioeconomic areas (ABS 2017).

Most endometriosis-related hospitalisations lasted 2 days or less

The average length of stay for endometriosis-related hospitalisations was almost 2 days (Table 1; Table S8). In around 4 in 10 (44%) hospitalisations, the patient was admitted to and separated from the hospital on the same day.

This may reflect that procedures undertaken during these hospitalisations are often same-day procedures. For example, 56% of endometriosis-related hospitalisations involved laparoscopic excision of lesion of pelvic cavity (a procedure in which lesions are removed by cutting), laparoscopic division of abdominal adhesions (a procedure in which adhesions are cut and divided), and/or laparoscopic diathermy of lesion of pelvic cavity (a procedure in which lesions are removed by burning), which are often same-day procedures.

Table 1: Length of stay for endometriosis-related hospitalisations, 2016–17

Length of stay	Endometriosis-related hospitalisations	Hospitalisations with endometriosis as the principal diagnosis	Hospitalisations with endometriosis as an additional diagnosis only
		%	
Same-day	43.7	43.2	44.2
1–2 days	39.0	44.0	33.7
3–4 days	12.8	9.5	16.3
5–6 days	2.9	2.3	3.6
7+ days	1.6	1.0	2.1
Total	**100.0**	**100.0**	**100.0**
		Mean (days)	
Length of stay	1.8	1.6	2.1
Length of stay, excluding same-day hospitalisations	2.4	2.0	2.9

Source: AIHW analysis of NHMD; Table S8.

Other reproductive conditions were common co-occurring diagnoses

Female pelvic peritoneal adhesions were the most common co-occurring diagnosis, recorded in 15% of endometriosis-related hospitalisations (Table 2; Table S9).

Nearly 1 in 10 (9.4%) endometriosis-related hospitalisations had a co-occurring diagnosis of excessive and frequent menstruation with regular cycle. There was a similar percentage with a co-occurring diagnosis of peritoneal adhesions (8.8%), unspecified leiomyoma of uterus (a type of non-cancerous tumour) (8.8%), pelvic and perineal pain (8.0%) and unspecified female infertility (7.9%).

Around 1 in 20 (5.1%) had a co-occurring diagnosis of insertion of a contraceptive device; the same percentage had a co-occurring diagnosis of other and unspecified ovarian cysts. There was a similar percentage with a co-occurring diagnosis of unspecified dysmenorrhoea (period pain) (5.0%) and polyp of corpus uteri (growths attached to the wall of the uterus; also known as endometrial polyps) (4.6%).

Note that 1 or more diagnoses could be reported for each hospitalisation—additional diagnoses are reported if the condition affects patient management.

Table 2: Most common co-occurring diagnoses among endometriosis-related hospitalisations, 2016–17 (% of hospitalisations)

Rank	Most common co-occurring diagnoses in endometriosis-related hospitalisations	Most common co-occurring diagnoses when endometriosis was the principal diagnosis	Most common co-occurring diagnoses when endometriosis was an additional diagnosis only
1	Female pelvic peritoneal adhesions (N73.6), 15.1%	Female pelvic peritoneal adhesions (N73.6), 16.7%	Excessive and frequent menstruation with regular cycle (N92.0), 16.6%
2	Excessive and frequent menstruation with regular cycle (N92.0), 9.4%	Peritoneal adhesions (K66.0), 9.2%	Pelvic and perineal pain (R10.2), 14.7%
3	Peritoneal adhesions (K66.0), 8.8%	Insertion of contraceptive device (Z30.1), 6.5%	Leiomyoma of uterus, unspecified (D25.9), 14.0%
4	Leiomyoma of uterus, unspecified (D25.9), 8.8%	Leiomyoma of uterus, unspecified (D25.9), 4.0%	Female pelvic peritoneal adhesions (N73.6), 13.3%
5	Pelvic and perineal pain (R10.2), 8.0%	Other and unspecified ovarian cysts (N83.2), 3.7%	Female infertility, unspecified (N97.9), 12.6%
6	Female infertility, unspecified (N97.9), 7.9%	Nausea and vomiting (R11), 3.7%	In vitro fertilisation (Z31.2), 8.6%
7	Insertion of contraceptive device (Z30.1), 5.1%	Female infertility, unspecified (N97.9), 3.6%	Peritoneal adhesions (K66.0), 8.5%
8	Other and unspecified ovarian cysts (N83.2), 5.1%	Polyp of corpus uteri (N84.0), 3.2%	Dysmenorrhoea, unspecified (N94.6), 8.3%
9	Dysmenorrhoea, unspecified (N94.6), 5.0%	Other noninflammatory disorders of ovary, fallopian tube and broad ligament (N83.8), 2.8%	Other and unspecified ovarian cysts (N83.2), 6.6%
10	Polyp of corpus uteri (N84.0), 4.6%	Excessive and frequent menstruation with regular cycle (N92.0), 2.7%	Polyp of corpus uteri (N84.0), 6.2%

Notes

1. Co-occurring diagnoses exclude other diagnoses of endometriosis and ICD-10-AM codes Z72.0 (tobacco use, current) and Z86.43 (personal history of tobacco use disorder).
2. Shading corresponds to the ICD-10-AM chapter each diagnosis belongs to—blue corresponds to *Neoplasms*; green to *Diseases of the digestive system*; pink to *Diseases of the genitourinary system*; purple to *Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified*; and orange to *Factors influencing health status and contact with health services*.

Source: AIHW analysis of NHMD; Table S9.

Among the hospitalisations with endometriosis as an additional diagnosis only, the most common principal diagnoses were:

- excessive and frequent menstruation with regular cycle (13% of these hospitalisations)
- pelvic and perineal pain (12%)
- unspecified female infertility (10%)
- in vitro fertilisation (8.6%)
- unspecified leiomyoma of uterus (a type of non-cancerous tumour) (6.1%)
- unspecified dysmenorrhoea (period pain) (5.0%)
- benign neoplasm of ovary (a non-cancerous tumour) (3.4%)
- other and unspecified ovarian cysts (2.7%)
- other specified abnormal uterine and vaginal bleeding (2.3%)
- intramural leiomyoma of uterus (fibroids growing within the wall of the uterus) (1.7%) (Table S10).

Diagnostic hysteroscopy was undertaken in 2 in 5 endometriosis-related hospitalisations

In 2016–17, 95% of endometriosis-related hospitalisations involved at least 1 procedure.

The most common procedures were:

- diagnostic hysteroscopy, a procedure used to examine the inside of the uterus
- dilation and curettage of the uterus, a procedure in which the lining of the uterus is scraped away
- laparoscopic excision of lesions of the pelvic cavity, a procedure in which lesions are removed by cutting
- laparoscopic division of abdominal adhesions, a procedure in which adhesions are cut and divided
- laparoscopic diathermy of lesions of the pelvic cavity, a procedure in which lesions are removed by burning
- tests for tubal patency, a procedure used in investigating infertility
- insertion of an intrauterine device, a procedure to insert a contraceptive device, which is also used in the treatment of endometriosis
- cystoscopy, a procedure used to examine the inside of the bladder
- physiotherapy
- unilateral laparoscopic ovarian cystectomy, a procedure used to remove ovarian cysts (Table 3; Table S11).

Note that for each hospitalisation, no procedures, or 1 or more than 1, could be undertaken.

‘Diagnostic hysteroscopy’ is the name of a procedure in the ACHI and does not imply that this procedure is being used to diagnose endometriosis.

Table 3: Most common procedures undertaken among endometriosis-related hospitalisations, 2016–17 (% of hospitalisations)

Rank	Most common procedures in endometriosis-related hospitalisations	Most common procedures when endometriosis was the principal diagnosis	Most common procedures when endometriosis was an additional diagnosis only
1	Diagnostic hysteroscopy (35630-00), 38.0%	Diagnostic hysteroscopy (35630-00), 44.4%	Diagnostic hysteroscopy (35630-00), 31.0%
2	Dilation and curettage of uterus [D&C] (35640-00), 33.1%	Laparoscopic excision of lesion of pelvic cavity (35637-10), 40.7%	Dilation and curettage of uterus [D&C] (35640-00), 29.7%
3	Laparoscopic excision of lesion of pelvic cavity (35637-10), 31.6%	Dilation and curettage of uterus [D&C] (35640-00), 36.2%	Laparoscopic excision of lesion of pelvic cavity (35637-10), 21.8%
4	Laparoscopic division of abdominal adhesions (30393-00), 20.0%	Laparoscopic division of abdominal adhesions (30393-00), 22.6%	Laparoscopic division of abdominal adhesions (30393-00), 17.1%
5	Laparoscopic diathermy of lesion of pelvic cavity (35637-02), 19.1%	Laparoscopic diathermy of lesion of pelvic cavity (35637-02), 21.0%	Laparoscopic diathermy of lesion of pelvic cavity (35637-02), 17.1%
6	Test for tubal patency (35703-00), 17.6%	Test for tubal patency (35703-00), 19.2%	Test for tubal patency (35703-00), 15.8%
7	Insertion of intrauterine device [IUD] (35503-00), 10.9%	Insertion of intrauterine device [IUD] (35503-00), 13.7%	Cystoscopy (36812-00), 10.6%
8	Cystoscopy (36812-00), 9.6%	Cystoscopy (36812-00), 8.6%	Allied health intervention, physiotherapy (95550-03), 10.5%
9	Allied health intervention, physiotherapy (95550-03), 8.9%	Laparoscopic ovarian cystectomy, unilateral (35638-04), 7.9%	Insertion of intrauterine device [IUD] (35503-00), 7.9%
10	Laparoscopic ovarian cystectomy, unilateral (35638-04), 7.5%	Allied health intervention, physiotherapy (95550-03), 7.4%	Laparoscopically assisted vaginal hysterectomy with removal of adnexa (35753-02), 7.6%

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) were not included in this analysis—these are companion procedures for many other procedures.
3. Shading corresponds to the ACHI chapter each procedure belongs to— blue corresponds to *Digestive system*; green to *Gynaecological procedures*; pink to *Urinary system*; and purple to *Non-invasive, cognitive and other interventions, not elsewhere classified*.

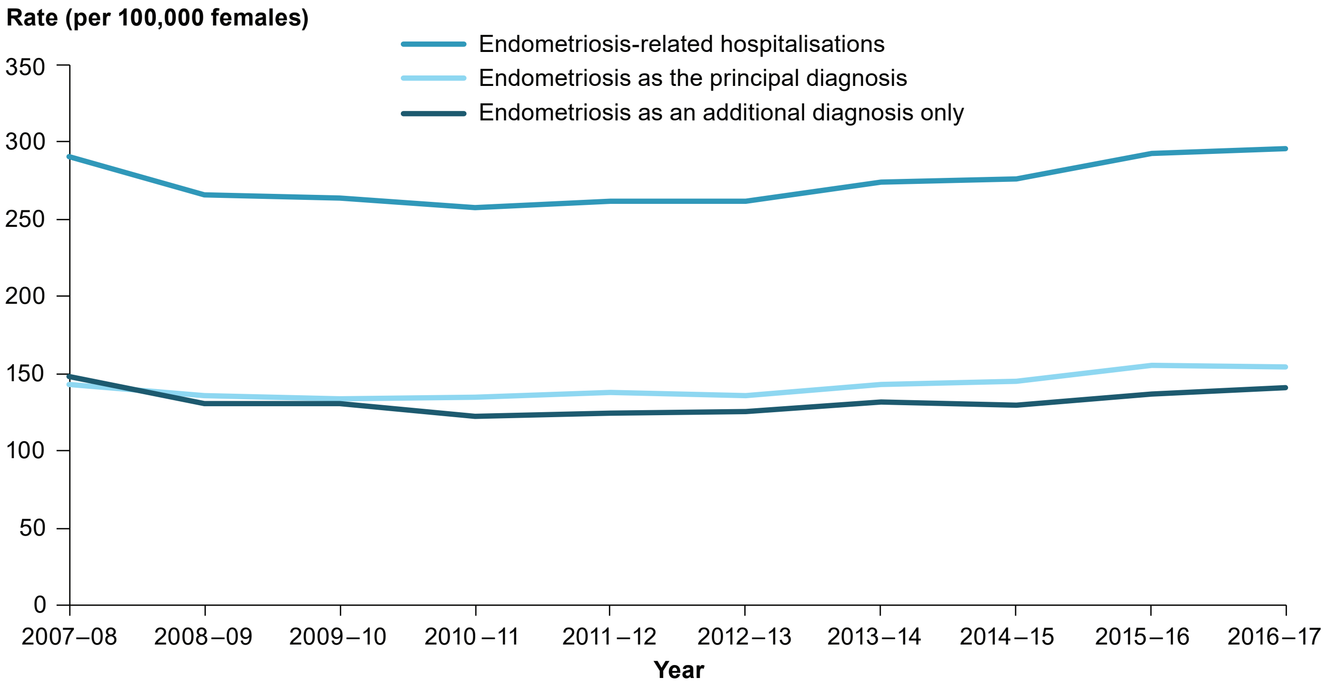
Source: AIHW analysis of NHMD; Table S11.

The rate of endometriosis-related hospitalisations rose slightly over time

After adjusting for differences in the age structure of the population, the rate of endometriosis-related hospitalisations rose slightly from 291 per 100,000 females in 2007–08 to 296 per 100,000 females in 2016–17 (Figure 5; Table S12).

This was driven by a rise in the rate of hospitalisations with endometriosis as the principal diagnosis; the rate of hospitalisations with endometriosis as an additional diagnosis only fell slightly over this period.

Figure 5: Age-standardised rate of endometriosis-related hospitalisations, 2007–08 to 2016–17



Source: AIHW analysis of NHMD; Table S12.

What are the data gaps?

There is a lack of information on the overall prevalence of endometriosis in the general population, as compared with the prevalence in specific cohorts of women. Such overall data could be provided by a question in a nationally representative survey asking 'Have you ever been told by a doctor or nurse that you have endometriosis?'. Similar questions related to other long-term conditions are asked in the Australian Bureau of Statistics' National Health Survey (ABS 2018). Information sourced in this way could provide a more robust estimate of the overall prevalence of endometriosis in the general population, which, in turn, could be used to inform policy, program and resourcing planning. However, estimates based on information sourced in this way would likely still provide an underestimate of the true prevalence of endometriosis, given the average delay between onset of symptoms and diagnosis.

There is also a lack of data related to endometriosis and primary care. Data from the Bettering the Evaluation and Care of Health program can provide information on how general practitioners manage endometriosis. However, the data are based on a sample of general practitioners, the number of visits related to endometriosis is relatively small and data collection ceased in 2015–16.

What are the opportunities for future work?

Endometriosis has several impacts other than hospitalisations, including pain, reduced fertility and reduced participation in school, work and sporting activities. Future work could examine these impacts, using data sources like the ALSWH. Previous analysis of the ALSWH has shown that endometriosis is associated with being infertile, with seeking advice for infertility and with using hormonal/in vitro fertilisation treatment for infertility (Herbert et al. 2009).

The analysis in this report described only hospital management of endometriosis, which likely reflects management of more severe symptoms. Future work could describe primary care, specialist care, pharmaceutical treatment and emergency department care for endometriosis. A potential source of information is linked data, which could be used to describe patient pathways and health service use in the years preceding and succeeding a diagnosis of endometriosis.

Although the National Action Plan for Endometriosis does not specifically cover related conditions (such as polycystic ovarian syndrome, pelvic inflammatory disease, and chronic pelvic and period pain), it does suggest that the identified research priorities could consider these conditions where appropriate. Future projects could replicate the analyses in this report for other conditions.

Recent waves of the Longitudinal Study of Australian Children collected data on the age at first period, period pain, and the impacts of periods on school, social activities, and sport or exercise. These data could be used to investigate the broader impacts of periods, noting that not all of these instances of period pain or impacts of periods would be due to endometriosis.

Glossary

Glossary terms are sourced from *Dorland's pocket medical dictionary* (Dorland 2013).

adhesion: A fibrous band or structure by which parts abnormally adhere.

corpus uteri: Body of uterus: that part of the uterus above the isthmus and below the orifices of the uterine tubes.

cyst: An abnormal closed epithelium-lined cavity in the body, containing liquid or semisolid material.

cystectomy: Excision of a cyst.

cystoscopy: Visual examination of the urinary tract with an endoscope.

diathermy: The heating of body tissues.

dilation and curettage: Expanding of the ostium uteri to permit scraping of the walls of the uterus.

dysmenorrhoea: Painful menstruation.

hysterectomy: Excision of the uterus.

hysteroscope: An endoscope for direct visual examination of the cervical canal and uterine cavity.

intramural: Within the wall of an organ.

intrauterine: Within the uterus.

laparoscopy: Examination or treatment of the interior of the abdomen by means of a laparoscope.

laparotomy: Incision through the abdominal wall.

leiomyoma: A benign tumour derived from smooth muscle.

lesion: Any pathological or traumatic discontinuity of tissue or loss of function of a part.

menopause: Cessation of menstruation.

neoplasm: Tumour.

perineal: Pertaining to the **perineum**.

perineum: The region and associated structures occupying the pelvic outlet and beneath the pelvic diaphragm.

peritoneal: Pertaining to the **peritoneum**.

peritoneum: The serous membrane lining the walls of the abdominal and pelvic cavities.

polyp: An abnormal protruding growth from a mucous membrane.

References

ABS (Australian Bureau of Statistics) 2017. Health service usage and health related actions, Australia, 2014–15. ABS cat. no. 4364.0.55.002. Canberra: ABS.

ABS 2018. National Health Survey: first results, 2017–18. ABS cat. no. 4364.0.55.001. Canberra: ABS.

ACCD (Australian Consortium for Classification Development) 2014. The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM)—9th edn.—tabular list of diseases, and Alphabetic index of diseases. Adelaide: Independent Hospital Pricing Authority.

ACCD 2015. The Australian Classification of Health Interventions (ACHI)—9th edn.—Tabular list of interventions, and Alphabetic index of interventions. Adelaide: Independent Hospital Pricing Authority.

AIHW (Australian Institute of Health and Welfare) 2018. Admitted patient care 2016–17: Australian hospital statistics. Health services series no. 84. Cat. no. HSE 201. Canberra: AIHW.

American Society for Reproductive Medicine 1997. Revised American Society for Reproductive Medicine classification of endometriosis: 1996. Fertility and Sterility 67:817–21.

Department of Health 2018. National Action Plan for Endometriosis. Canberra: Department of Health.

Dorland W 2013. Dorland's pocket medical dictionary. Philadelphia: Elsevier Saunders.

Dunselman G, Vermeulen N, Becker C, Calhaz-Jorge C, D'Hooghe T, De Bie B et al. 2014. ESHRE guideline: management of women with endometriosis. Human Reproduction 29:400–12.

Ernst & Young 2019. The cost of endometriosis in Australia. Sydney: Ernst & Young.

Fuldeore M & Soliman A 2017. Prevalence and symptomatic burden of diagnosed endometriosis in the United States: national estimates from a cross-sectional survey of 59,411 women. Gynecologic and Obstetric Investigation 82:453–61.

Herbert D, Lucke J & Dobson A 2009. Infertility, medical advice and treatment with fertility hormones and/or in vitro fertilisation: a population perspective from the Australian Longitudinal Study on Women's Health. Australian and New Zealand Journal of Public Health 33:358–64.

Jean Hailes for Women's Health 2017a. Endometriosis complications. Melbourne: Jean Hailes for Women's Health. Viewed 10 April 2019, <https://jeanhailes.org.au/health-a-z/endometriosis/complications>.

Jean Hailes for Women's Health 2017b. Endometriosis symptoms & causes. Melbourne: Jean Hailes for Women's Health. Viewed 21 May 2019, <https://jeanhailes.org.au/health-a-z/endometriosis/symptoms-causes>.

Johnson N, Hummelshoj L, Adamson G, Keckstein J, Taylor H, Abrao M et al. 2017. World Endometriosis Society consensus on the classification of endometriosis. Human Reproduction 32:315–24.

Nnoaham K, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C et al. 2011. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. Fertility and Sterility 96:366–73.

Pugsley Z & Ballard K 2007. Management of endometriosis in general practice: the pathway to diagnosis. British Journal of General Practice 57:470–6.

Treloar S, O'Connor D, O'Connor V & Martin N 1999. Genetic influences on endometriosis in an Australian twin sample. Fertility and Sterility 71:701–10.

Vercellini P, Fedele L, Aimi G, Pietropaolo G, Consonni D & Crosignani P 2007. Association between endometriosis stage, lesion type, patient characteristics and severity of pelvic pain symptoms: a multivariate analysis of over 1000 patients. Human Reproduction 22:266–71.

Ware V-A 2013. Improving the accessibility of health services in urban and regional settings for Indigenous people. Resource sheet no. 27. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.

Wheeler J 1989. Epidemiology of endometriosis-associated infertility. Journal of Reproductive Medicine 34:41–6.

Young A, Dobson A & Byles J 2000. Access and equity in the provision of general practitioner services for women in Australia. Australian and New Zealand Journal of Public Health 24:474–80.

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