The cost of endometriosis in Australia

A report for EndoActive

Reliance Restricted

29 May 2019

EndoActive

EY
Building a better working world

Dashboard
NOTICE

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

NOTICE

Ernst & Young was engaged on the instructions of EndoActive (“Client”) to prepare an independent report on the estimated economic impact of endometriosis in Australia (“Report”), in accordance with our engagement letter dated 2 May 2017.

The results of Ernst & Young’s work, including the assumptions and qualifications made in preparing the report, are set out in Ernst & Young's report dated 29 May 2019 ("Report"). The Report should be read in its entirety, the applicable scope of the work and any limitations. A reference to the Report includes any part of the Report. No further work has been undertaken by Ernst & Young since the date of the Report to update it.

Ernst & Young has prepared the Report for the benefit of EndoActive and has considered only the interests of EndoActive. Ernst & Young has not been engaged to act, and has not acted, as advisor to any other party. Accordingly, Ernst & Young makes no representations as to the appropriateness, accuracy or completeness of the Report for any other party's purposes.

No reliance may be placed upon the Report or any of its contents by any party other than EndoActive (“Third Parties”). Any Third Party receiving a copy of the Report must make and rely on their own enquiries in relation to the issues to which the Report relates, the contents of the Report and all matters arising from or relating to or in any way connected with the Report or its contents.

Ernst & Young disclaims all responsibility to any Third Parties for any loss or liability that the Third Parties may suffer or incur arising from or relating to or in any way connected with the contents of the Report, the provision of the Report to the Third Parties or the reliance upon the Report by the Third Parties.

No claim or demand or any actions or proceedings may be brought against Ernst & Young arising from or connected with the contents of the Report or the provision of the Report to the Third Parties. Ernst & Young will be released and forever discharged from any such claims, demands, actions or proceedings.

Ernst & Young have consented to the Report being published electronically on the EndoActive website for informational purposes only. Ernst & Young have not consented to distribution or disclosure beyond this. The material contained in the Report, including the Ernst & Young logo, is copyright and copyright in the Report itself vests in EndoActive. The Report, including the Ernst & Young logo, cannot be altered without prior written permission from Ernst & Young.

Ernst & Young’s liability is limited by a scheme approved under Professional Standards Legislation.

Dashboard
About EndoActive

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

The Cost of Endometriosis in Australia Report

Foreword by EndoActive

The impact of endometriosis extends beyond the personal pain and distress experienced by the patient. It impacts on her partner, her family and community interactions and on her education and career, sexual relationships, fertility and mental and psychosocial health.

We are well aware of the many ways that endo has shattered dreams, disrupted lives and trapped hundreds of thousands of women in the clutches of chronic pelvic pain and other debilitating physical symptoms that can ultimately lead to despair, isolation and poverty.

EndoActive understands that endo affects not only women and girls but also transgender, non-binary, and gender-diverse people assigned female at birth. Data for these other people has not been available for the purposes of this report.

Understanding how endo impacts the Australian economy underpins the objectives in The National Action Plan for Endometriosis 2018 and supports strategies that will lead to better health outcomes for patients and research that will perhaps ultimately lead to a cure.

EndoActive is immensely grateful to EY for their generous pro-bono support and for their understanding and expertise in preparing this report in particular Bonnie Barker, Cameron Bird, Kirsten Callander, John Cochrane, Sarah Chancellor-Goddard, Richa Bhatia Nirman, Megan Paybody and Tom Steel. They have applied their rigorous analysis to measuring the impact of a disease that is still emerging from the shadows of ignorance, shame and misunderstanding. This investment will ultimately benefit patients as well as the wider endo community including clinicians, researchers and scientists.

We thank Professor Grant Montgomery, Institute of Molecular Bioscience, and Professor Gita Mishra, University of Queensland, for their expertise and support.

We acknowledge The Pelvic Pain Report 2011 by Dr Susan Evans, Deborah Bush MNZM QSM, Professor Thierry Vancaillie and Painaustralia for their contributions to earlier estimations of the economic burden of pelvic pain.

EndoActive thanks the many endo patients who have generously shared their stories and allowed us to include their quotes in this report.

Lesley & Syl Freedman

Co-founders EndoActive

About EndoActive

EndoActive, founded in 2014, is a registered health promotion charity advocating for women and girls with Endometriosis (endo), raising awareness, conducting research and providing evidence-based information. EndoActive convened the first Australian conferences - Shared Perspectives on Endometriosis - for patients and health care professionals. EndoActive belongs to the World Endometriosis Organisations (WEO), founding member of ACE (Australian Coalition for Endometriosis) and serves on the Endometriosis Advisory Group for the National Action Plan for Endometriosis July 2018.

Dashboard
Table of contents

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Dashboard

Page 2

Executive summary

1

Page 5

Introduction

2

Page 9

Methodology for estimates

3

Page 13

Direct and indirect costs

4

Page 15

Other impacts

5
The broader (non-quantifiable impacts of endo)

Page 25

Appendix A

6
Detailed methodology

Page 28

Appendix B

7
References

Page 36

1

Executive summary

1 Executive summary
About this report

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

About this report

This report offers a high level insight into the economic cost of endometriosis (also referred to as 'endo') in Australia. Insights are based on existing Australian and international research about the prevalence of endo, services used by individuals with endo and broader impacts of endo on individuals' lives. This report provides a holistic view of the impact of endo in the Australian community. This includes both the direct medical and associated costs and in-direct economic costs associated with endo and provides qualitative analysis of the additional impact of endo on patients and their families.

What is endo?

Endo is a chronic condition associated with pelvic pain and infertility, characterised by tissue similar to the lining of the uterus growing in other parts of the body. Endo is found in many diverse forms, from limited superficial endometrial implants to severe conditions infiltrating different organs and inducing pain and infertility as main problems. It can affect all women and girls from pre-pubescence to beyond menopause, irrespective of their age, background or lifestyle. The disease affects approximately 7-10% of Australian women of reproductive age, with an estimated 619,924 Australian women suffering from endo at some point in their life[14]. This can include girls as young as seven, however we have restricted this report to analyse costs for women aged between 15 and 51 to be consistent with assumptions drawn from academic literature.

Economic costs included in this report

Categories of costs considered in the estimation of the economic cost of endo in Australia in this report include: burden of disease (the value associated with living with an illness), healthcare costs, non-healthcare costs (i.e. decreased workplace productivity as a result of the chronic pain caused by the disease) and deadweight loss.

Not all costs likely to be incurred by girls and women with endo have been included in this report due to data limitations and limited existing research. Therefore many of the costs included can be thought of as conservative and require further research. A significant gap includes the medical expenses incurred whilst girls and women seek diagnosis (which can take many years). These also may include pharmaceutical costs, comorbidity costs, impacts on unemployment, impacts on education and carers leave. Unquantified costs of endo have been qualitatively described throughout this report.

The reduction in the quality of life for women diagnosed with endo has been valued per year at

$4.04 billion

Up to 1 in 2

Women with endo have fertility problems[8]

1 in 10

Australian women will suffer from Endo at some point in their life[14]

$506.4 million

in direct healthcare costs to diagnose and treat endo in FY2018.

> ***"Overall endo has made my life a very solitary life"***
>
> *- Endo patient[25]*

$2.6 billion

productivity losses

On average, women suffering from endo use

60% of their sick leave *due to the chronic pain they experience*

Total economic impact of endo on the Australian economy in FY2018

= $7.4 billion

1 Executive summary
Economic cost summary

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

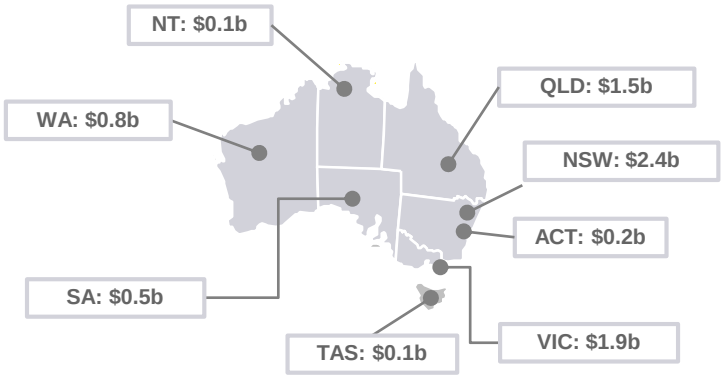
The total economic cost of endo was estimated to be approximately **$7.4 billion in FY2018**. The majority of this cost is directly attributed to the burden of disease on women and productivity losses to the economy driven by an increased rate of absenteeism and presenteeism.

$7.4 billion

attributed to the total cost of endo to the Australian economy in FY2018.

Costs across Australia

Assuming endo affects 10% of women each year*, the greatest cost of endo sits within the states and territories with the largest female populations.



* See Page 12 for more details on prevalence of endo in Australia

Who fronts the bill

The Australian health system involves multiple interlinked layers of policy and funding responsibilities. These can sit separately with different parties such as governments, individuals and private health insurers. The costs of endo are shared by all.

Burden of Disease

Burden of Disease measures the impact of living with illness and injury and dying prematurely. It is used to quantify the 'burden' of living at a less than optimal level of health. This figure is used to quantify the reduction in quality of life for individuals with endo.

$4 billion

Direct healthcare costs

Direct healthcare costs include the costs associated with engaging with health services as a result of being diagnosed with endo. This includes hospital admissions, emergency room visits, physician visits, gynaecologist visits and other health specialists and surgeries. The payment of these costs falls upon both state and federal budgets, individuals through co-payments and private health insurers.

$506.4 million

Healthcare related transport

These costs refer to the non-healthcare related financial burden on individuals suffering endo. This primarily includes the cost of transport to healthcare services.

$75.1 million

Productivity loss

These costs include cost to employers from absenteeism and presenteeism – also including loss of wages for individuals who are not afforded sick leave.

$2.6 billion

Deadweight loss of taxation

The deadweight loss of taxation measures the cost to society of the taxation required for the government to fund the direct healthcare expenses for those diagnosed with endo.

$139.3 million

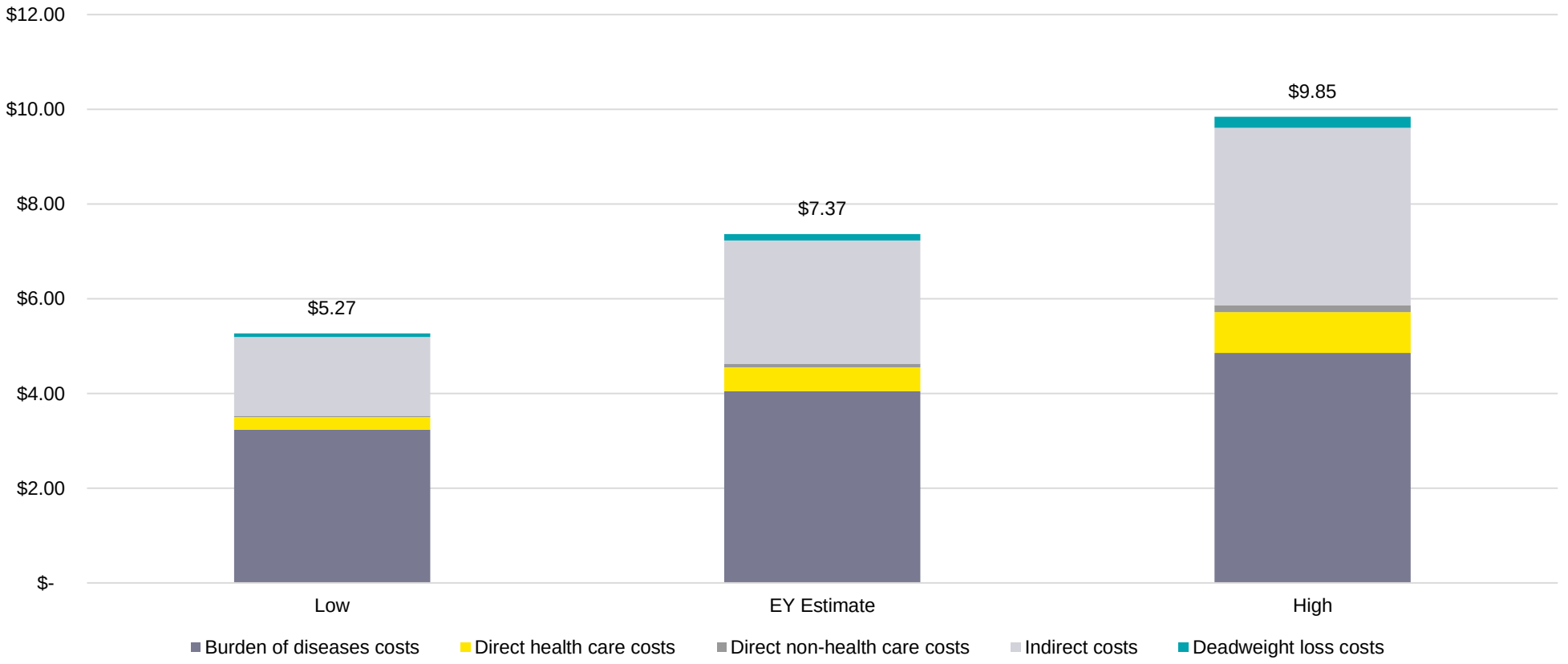
1 Executive summary
Sensitivity analysis

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

This analysis presented throughout this report is based on a number of studies, literature from both Australia and overseas as well as a number of assumptions extracted from similar studies and primary research.

The core results presented reflect our best estimate of the economic cost of endometriosis, however in order to cater for uncertainties within the assumptions we have undertaken sensitivity analysis and present this through the low and high estimates shown in the figure below. These scenarios test a range of assumptions including, for example the prevalence rate in Australia, which given the nature of the disease and widespread underdiagnoses is relatively uncertain. The low scenario assumes a prevalence rate of 8% increasing to 12% in the high scenario.

In the low scenario the total cost of endo is approximately $5.27 billion per year, increasing to $9.85 billion per year in the high scenario.



2

Introduction

2 Introduction
About endometriosis

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

About endometriosis

Endometriosis (endo) is a chronic disease associated with pelvic pain and infertility. Despite affecting approximately 7-10% of Australian women and girls[14], it is commonly undiagnosed due to a poor understanding of the disease. A further barrier to diagnosis is the requirement for invasive surgery to confirm the presence of endo.

Endo is present when the tissue that is similar to the lining of the uterus (womb) occurs outside this layer and causes pain and/or infertility. The disease and its associated pain often has a severe impact on the physical and mental health and wellbeing, quality of life and social functioning of the women suffering with endo and their families.

Symptoms

The symptoms of endo are highly variable in nature and severity. In addition to severe pain and infertility, other common symptoms include:

- Abnormal menstrual bleeding patterns
- Painful abdominal bloating
- Other gastrointestinal and urinary symptoms
- Extreme lethargy.

Diagnosis

For patients suspected of suffering from endo, laparoscopic surgery allows a doctor to see inside the abdomen and assess the organs of the patient. A laparoscopy can magnify the tissues and even small amounts of the disease can be seen. Tissue that is thought to contain endo is removed at the time of the laparoscopy and sent to a pathologist to be viewed under a microscope to confirm the diagnosis. While ultrasounds and MRI scans can be used to investigate the condition, laparoscopic surgery and having a biopsy taken is the only way to reach a definitive diagnosis.[23]

Treatment

There is **no permanent cure** for endo and current treatment approaches potentially only cause a brief respite from the symptoms. There are three typical kinds of treatments for the management of endo:

1. Medication

2. Surgery

3. Allied health treatments (physiotherapy, psychology, dietetics, etc.) and complimentary medicine.

There is no known ‘best treatment’. There are advantages and disadvantages of each treatment and each patient may require several different types of treatments before identifying the right combinations of treatments for them.

Previous studies

Whilst there is limited existing research on endo in Australia, a number of international studies have sought to estimate usage of health services by women and girls diagnosed with endo. Key insights from existing research include:

- The prevalence of endo is estimated to be between 5% and 10% of women in their reproductive years.[30]
- The delay between onset and diagnosis is, on average, between 7 and 12 years.[13]
- 94% of patients report one or more comorbidities including infertility, chronic pain, migraines and depression.[21]

2 Introduction
Purpose of this report

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Purpose of this report

This report seeks to build the level of understanding and awareness of the economic costs associated with endo in Australia. It is hoped the insights derived from this report will continue to drive support for the ongoing investment into further research and education initiatives surrounding endo.

In line with the National Action Plan, this report is intended to provide a robust evidence base to establish the case for change and highlight the financial and non-financial costs endo imposes on the Australian community.

Why this report is needed

This report is needed to highlight the impact and economic costs of endo in Australia. There is limited information on the impact of endo in an Australian context, yet the available data strongly suggests that endo adds a significant 'silent' burden to the nation's budget. Detailing the economic burden of endo provides insight into the significant impact endo has on the community and it is hoped to encourage further funding for endo related research and support.

This report supports one of the plan's recommendations to conduct further research to understand the impact of endo, including the financial impact on the individual and estimated social and economic participation loss.

National Action Plan for Endometriosis

The National Action Plan for Endometriosis (the Plan) was launched in July 2018. It acknowledges the historic failures in the awareness, diagnosis and treatment of the chronic condition. The Plan is a national blueprint seeking to improve the treatment, understanding and awareness of endo, marking a significant step forward for patients. The table below outlines the Plan's three areas.

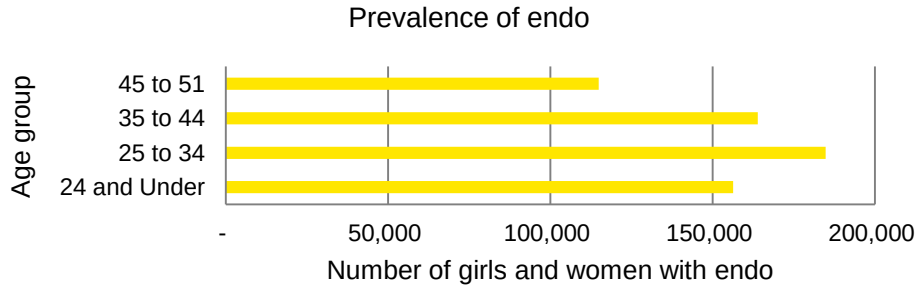
The Plan's Priority areas	Key actions
Awareness and education	► Develop widespread, visible and context-specific community awareness campaigns delivered through multiple channels ► Promote early education on women's health, delivered in school settings, and provided for all genders ► Improve access to information, self-education and self-management tools for individuals living with endo at all stages of their journey ► Improve awareness and understanding of endo among health professionals working at every stage in the clinical pathway
Clinical management and care	► Develop clinical guidelines and clinical care standards to promote integrative care for all stages of the care pathway. ► Target diagnostic delay and promote early access to intervention, care and treatment options ► Improve the affordability, accessibility and national consistency of management and care options throughout Australia ► Ensure endo is recognised as a chronic condition by all health practitioners, acknowledging its physical, psychological and social impacts ► Narrow the gap in quality of life between endo patients and their peers
Research	► Build a collaborative environment that enables world-leading research on endo ► Mine existing data and improve data linkage between sources to improve understanding of the current state of endo in Australia ► Conduct further research to understand the causes and impacts of endo and progress towards the development of a cure

2 Introduction
Prevalence in Australia

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

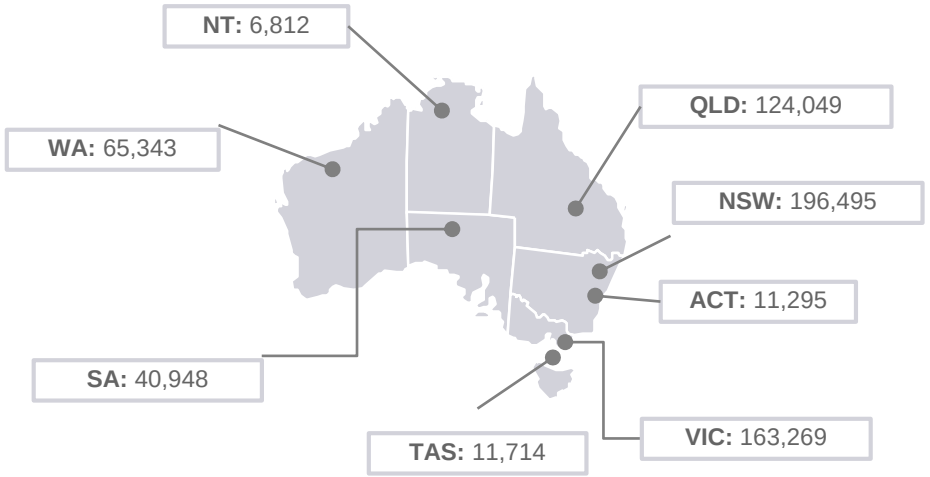
Prevalence in Australia

Previous research estimates prevalence of endo within the community is around 10% of all women of reproductive age[14]. This can include girls as young as 7 years old, however the costs captured within this analysis have been restricted to women aged 15 – 51 years. This approximates to around 619,924 girls and women in Australia in FY2018.



States and Territories

Assuming endo affects 1 in 10 women, it is estimated that New South Wales and Victoria have the highest proportion of women affected (given these states have the largest female populations).



Accuracy of prevalence estimates

Prevalence estimates of 10% used in this study may be underestimated given the difficulties in definitively diagnosing endo and the rate of undiagnosed cases within the community.

Studies have shown that, on average, a 7-12 year delay exists between onset and diagnosis with many girls and women suffering from the disease never receiving diagnosis.[13]

This widespread underdiagnoses means that the assumption of 10% prevalence of the disease may be a conservative figure, which fails to capture all women suffering from the condition.

> ***"I suffered with the pain and it was bad. I'd been telling my GP since I was 13 years old something was wrong…everyone pretty much thought I was just being a sook until I was diagnosed at 21"***
>
> *- Endo patient*[25]

Previous studies and international estimates

Prevalence estimate	Country	Source
6% - 10%	Multiple countries	Soliman et al, 2016[34]
5% - 10%	Denmark	Hansen, 2012[17]
10%	Multiple countries	Nnoaham et al, 2011[26]
7.23%	Australia	Treloar et al, 1999[35]

3

Methodology for estimates

3 Methodology for estimates
Methodology overview

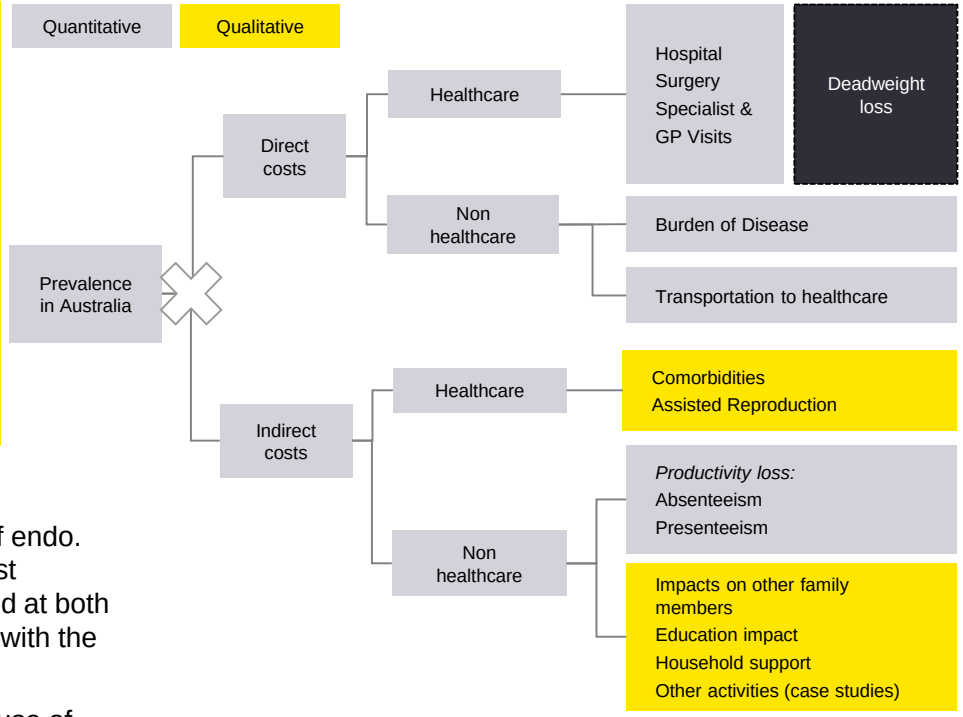
Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Broad Methodology

Estimation of the economic cost of endo was calculated by multiplying the estimated number of women in Australia suffering endo within a year by the direct and indirect costs including:

- Burden of disease (the monetary value associated with living with an illness)
- Direct costs included both healthcare and non-healthcare costs such as hospitalisation, surgery and travel to healthcare
- Indirect costs also included costs such as absenteeism, presenteeism.

Qualitative costs highlighted on the right have not been quantified and are instead described in Section 5.



Uniqueness of our approach

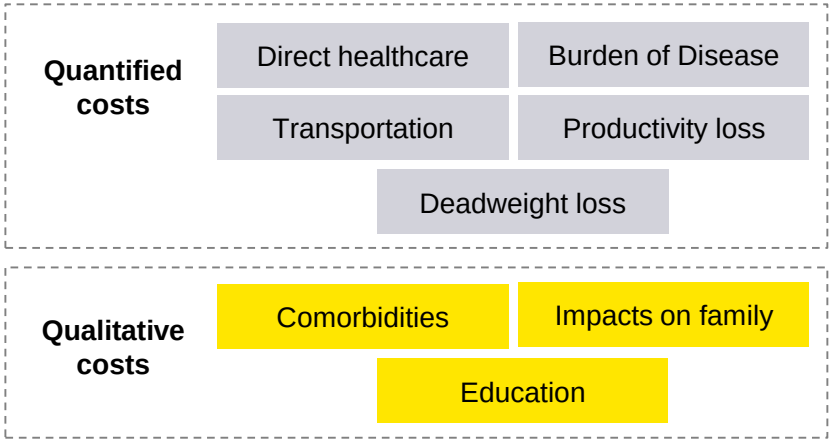
We have taken a highly disaggregated approach to estimating the economic cost of endo. Healthcare costs can be disaggregated by emergency room visits, GP and specialist healthcare visits, medication usage and surgeries. Productivity costs were estimated at both a state and age level, offering a highly detailed view of productivity loss associated with the disease.

We used international academic literature to determine assumptions on the typical use of healthcare services, medication, ED presentations and surgeries. Similarly, assumptions on the loss of productivity across different age groups was sourced from academic literature and applied to Australian population and labour force statistics.

Limitations of our approach

In the absence of Australian studies, many of our assumptions in our modelling are based on studies conducted outside of Australia, within potentially different healthcare settings and at different time periods. These assumptions have all been detailed in Appendix A and take a conservative approach where possible.

Due to the lack of research and available data, some costs have not been quantified and instead have been qualitatively explained. For example, patient co-payments for specialist healthcare consultation and costs associated with medications has not been included due to lack of available data. Therefore, our estimates reflect a conservative estimation of the total economic cost of endo in Australia.



4

Direct and indirect costs

4 Direct and indirect costs
Economic cost summary

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

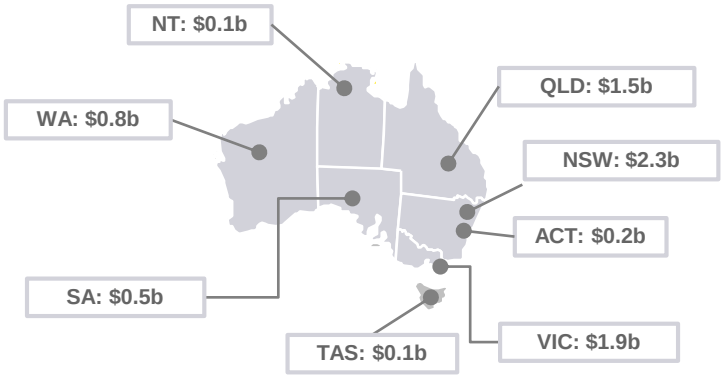
The total economic cost of endo was estimated to be approximately **$7.4 billion in FY2018**. The majority of this cost is directly attributed to the burden of disease on women and productivity losses to the economy driven by an increased rate of absenteeism and presenteeism.

$7.4 billion

attributed to the total cost of endo to the Australian economy in FY2018.

Costs across Australia

Assuming endo affects 10% of women each year*, the greatest cost of endo sits within the states and territories with the largest female populations.



* See Page 12 for more details on prevalence of endo in Australia

Who fronts the bill

The Australian health system involves multiple interlinked layers of policy and funding responsibilities. These can sit separately with different parties such as governments, individuals and private health insurers. The costs of endo are shared by all.

Burden of Disease

Burden of Disease measures the impact of living with illness and injury and dying prematurely. It is used to quantify the 'burden' of living at a less than optimal level of health. This figure is used to quantify the reduction in quality of life for individuals with endo.

$4 billion

Direct healthcare costs

Direct healthcare costs include the costs associated with engaging with health services as a result of being diagnosed with endo. This includes hospital admissions, emergency room visits, physician visits, gynaecologist visits and other health specialists, prescriptions and surgeries. The payment of these costs falls upon both state and federal budgets, individuals through co-payments and private health insurers.

$506.4 million

Healthcare related transport

These costs refer to the non-healthcare related financial burden on individuals suffering endo. This primarily includes the cost of transport to healthcare services.

$75.1 million

Productivity loss

These costs include cost to employers from absenteeism and presenteeism – potentially also including loss of wages for individuals who are not afforded sick leave.

$2.6 billion

Deadweight loss of taxation

The deadweight loss of taxation measures the efficiency cost to society associated with the taxation required for the government to fund the direct healthcare expenses for those diagnosed with endo.

$139.3 million

4 Direct and indirect costs
Burden of disease

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

The burden of disease measures the impact of living with illness and injury and dying prematurely. It is used to quantify the 'burden' of living at a less than optimal level of health. The total estimate cost of burden of disease in FY2018 was estimated to be **$4 billion**. This accounts for approximately 55% of economic costs quantified in this report. See Page 28 for a detailed methodology on how these figures were derived.

What is burden of disease?

Burden of disease analysis is a technique used to assess and compare the impact of different diseases, conditions or injuries and risk factors on a population. It uses information from a range of sources to quantify the fatal and non-fatal effects of diseases in a consistent manner so that they can then be combined into a summary measure of health called disability adjusted life years, or DALY. DALY combines the impact of dying early and living with illness.

Burden of disease estimates capture both the quantity and quality of life, and reflect the magnitude, severity and impact of disease and injury within a population. For the purpose of this study, only the impact in 2018 has been included. However, studies have shown on average a 7-12 year delay exists between onset and diagnosis, demonstrating the reduction of quality of life often continues for many years[14].

$4 billion

attributed to the cost of all women in FY2018 for just one year of life living with endo.

Disability weight

A disability weight places a value on time lived in non-fatal health states, and quantifies societal preferences for different health states in relation to the societal ideal of good health. The weights are measured as a number on a scale from 0 to 1, and in this case 0 equals perfect health and 1 equals death. According to a 2005 study by the then Victorian Department of Human Services, endo has a disability weight of 0.033[36]. This weight assumed women experience mild to moderate pain for one week in four throughout a year and may be underestimated for women who experience more severe or more frequent pain.

Burden of disease over a lifetime

For an individual woman suffering endo, the monetary value ascribed to the reduction in her quality of life in today's dollars is approximately $6,529 for each year she suffers from endo.

This does not take into consideration the burden of co-morbidities. For example, it does not include costs associated with depression or the burden attributed to invasive treatments that may be required including hysterectomy or oophorectomy.

The total economic cost of endo in Australia estimated in this report is restricted to just the year 2018. Therefore the $4 billion estimate attributed to burden of disease is a sum of $6,529 for each girl and woman estimated to have endo within the year 2018.

If the onset of endo starts at age 15, the lifetime burden of disease is estimated to be approximately $129,993*.

$129,993

Attributed to the cost for one woman who suffers from endo over the course of her lifetime.

* This was estimated by discounting one woman's yearly burden of disease costs to present value (PV) between the ages of 15 and 51. Yearly PV costs were then summed to represent a total estimated cost of burden of disease over one woman's lifetime.

4 Direct and indirect costs
Productivity losses

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Productivity loss has been estimated based on the increased levels of absenteeism and presenteeism associated with endo. The total cost attributed to a loss of productivity due to endo in FY2018 is **$2.6 billion**. This accounts for approximately 35% of all costs quantified in this report. See Page 25 for a detailed methodology on how these figures were derived.

However, this is likely underestimated as it doesn't account for the productivity loss of carers who may need to exit the workforce to care for loved ones diagnosed with endo. This also doesn't include time off school or university.

What's included in productivity losses?

Women suffering endo may experience severe pain which causes them to be bedridden and unable to do daily tasks. This in turn also affects their ability to participate in the labour force.

Productivity losses were estimated in two parts. These included loss attributed to absenteeism and loss attributed to presenteeism. Absenteeism refers to a woman not attending work due to her disease. Presenteeism refers to a woman attending work, but not being as productive as usual due to her disease.

$2.6 billion

attributed to the total loss of productivity to the Australian economy driven by increased absenteeism and presenteeism.

Absenteeism

Endo can cause severe chronic pain which limits a woman's ability to attend work. It is estimated women on average are absent from work six days of the year due to their illness. This is based on the assumption women are absent from work on average between 0.4 and 1.31 days per week[32].

Assuming women are offered a standard 10 days sick leave per year from their employer and are absent from work six days of the year because of endo, this means more than half of their sick leave can be taken due to endo. This figure is typically higher for younger women who may take up to nine days off a year. It is estimated absenteeism costs the Australian economy approximately $422 million each year

60% of sick leave

is taken on average by women suffering endo because of the chronic pain they experience.

Presenteeism

Presenteeism is a cost to employers and the broader economy and accounts for approximately 84% of total productivity loss. Of the women suffering endo within the labour force, it is estimated 4.8 hours of productivity are lost on average per week[32]. Accounting for varying wages across age groups and the number of employed women in each state and territory across Australia, it is estimated presenteeism alone costs the Australian economy approximately $2.2 billion each year.

$2.2 billion

attributed to presenteeism as chronic pain limits the ability to be productive at work. This figure accounts for when women attend the workplace, but are performing at a sub-optimal level.

4 Direct and indirect costs
Productivity losses

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

What is not included in productivity losses?

Total productivity losses do not include: the cost attributed to unemployment caused by the suffering of chronic pain, the co-morbidities that come with the disease which may also impact on labour force engagement, time off work to seek treatment or recovery from surgical procedures or time off work to care for a child or loved one. Therefore the reported productivity loss estimate is likely to be underestimated.

Unemployment caused by chronic pain

Some women with endo can experience severe chronic pain which can cause them to be bedridden and limit their participation in the workforce. A 2009 study by the Australian Institute of Health and Welfare estimated people with chronic disease were 60% more likely to not participate in the labour force, were less likely to be employed full-time, and more likely to be unemployed, than those without chronic disease.[6]

Productivity loss caused by co-morbidities

Co-morbidities of endo such as depression, severe pain, digestion issues, migraines, chronic fatigue, stress, irritable bowel syndrome and pelvic inflammatory disease are all likely to significantly contribute to productivity losses. However, these co-morbidities are difficult to directly attribute to endo and so are unable to be credibly quantified without further research.

In the case of mental health, there is a bilateral relationship between unemployment and depression. Studies show severe depressive symptoms can be a consequence of unemployment and visa-versa.[7]

Time off work to seek treatment and recovery

Conservative direct healthcare assumptions estimated girls and women visited either a GP or gynaecologist or underwent a surgical procedure at least 1.4 times a year. Multiplying 1.4 by the number of girls and women in Australia estimated to have endo (619,942 girls and women), this amounts to approximately 883,967 million events a year girls and women's lives are disrupted to seek medical treatment. See Appendix A for further details on assumptions used to estimate direct healthcare expenditure.

Time off work to care for a child or loved one

The severe pain caused by endo can take away a girl or woman's independence, forcing them to rely on a parent, child or partner to care for them, transport them to medical appointments and assist them with everyday tasks.

There are more than 2.7 million unpaid carers in Australia, which means about one in eight people in Australia are carers. Of these 2.7 million carers, approximately 272,000 are under 25 years old. Around half of primary carers provide care for at least 20 hours a week[9]. Data does not currently exist to estimate the total number of carers in Australia assisting women and girls with endo, however anecdotal evidence suggests endo has a significant impact on family and personal lives.

Case study: ***Poor school attendance and limited employment options***

From ages 11 – 1 7, Mum took time off work to take me to medical appointments and care for me at home which we've estimated cost Mum approximately $6,000 - $7,000 in wages per year. From the time I was 17 to now, medical appointments and procedures, medications and time off work (not to mention limited income as my bad attendance at school cost me a spot in university scholarships) has cost me about $7,000 – $8,000 per year. Endo has had a huge financial impact on me. I often have to borrow money to cover costs and get by. My quality of living options have always been a challenge. I can't build up my savings as each time I do I have to use it due to running out of annual leave or sick leave. I ended up choosing not to go to university due to the extra costs and my potential to be absent from work. My job options are limited in that sense.

- Emily H., 2019

4 Direct and indirect costs
Direct healthcare

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

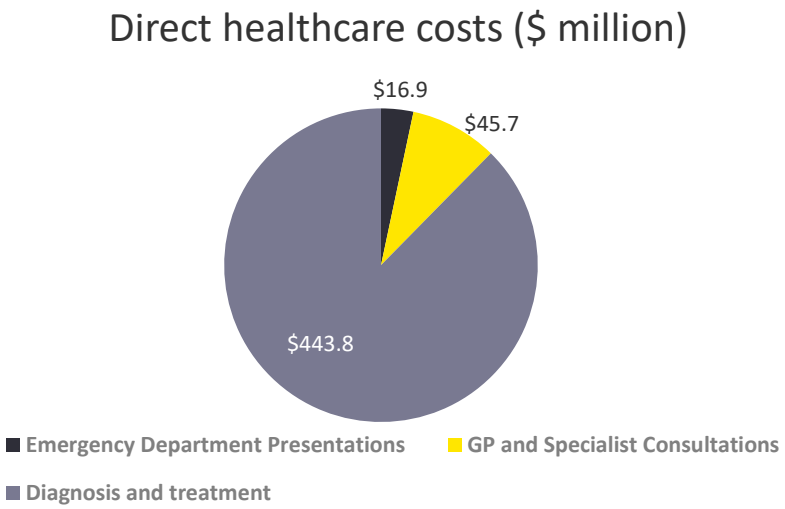
Direct healthcare costs are estimated to be approximately **$506.4 million** in FY2018. This includes costs to the health system attributed to hospital admissions, emergency room visits, physician visits, gynaecologist visits and other health specialists, prescriptions and surgeries. This does not however include the additional co-payments made by individuals or health insurers. See pages 24 - 28 for a detailed methodology on how these figures were derived.

What's included in direct healthcare?

The direct healthcare costs in this report include costs to the Medicare Benefits Scheme associated with GP visits, emergency room visits, specialist visits and surgeries.

Given the high variation in patient co-payments charged by health specialists in Australia, these costs have not been estimated but have been reported to be well over $100 for initial specialist consultations[24].

The cost of treating co-morbidities caused by endo such as depression have also not been included.



Diagnosis and treatment

Diagnosis of endo is typically undertaken through an invasive procedure called a laparoscopy[14]. This involves making small incisions on the abdomen and removing affected tissue inside the abdominal cavity. Once a woman is diagnosed, she has a variety of treatment options to choose from. However, there is no permanent cure and no guarantee that treatment options, including a hysterectomy, will relieve chronic pain. Surgical procedures included in the costs outlined in this report include laparotomies, laparoscopies, hysterectomies and oophorectomies. In FY2018, the cost of medical procedures associated with diagnosis and treatment of endo was approximately **$443.8 million**.

GP visits and specialist consultation

Women suffering from endo must be referred to a specialist via their GP. The cost of funding these frontline services alone in FY2018 was approximately **$45.7 million**.

However, given the lengthy delay in diagnosis for many women, this figure likely underestimates the true costs faced by women who are forced to visit their GP and specialists many times before they are finally diagnosed with endo. This delay can be as long as 12 years[14], during which time girls and women may be visiting emergency departments and seeing specialists before a diagnosis is made.

Hospital emergency departments

Assuming 5% of women with endo visit just one hospital emergency department a year, the total cost of emergency department visitation in FY2018 was **$16.9 million**.

4 Direct and indirect costs

Direct healthcare – costs not quantified

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

What is not included in direct healthcare costs?

The estimated cost of endo related to direct healthcare is likely underestimated given the lengthy delay in diagnosis for many women and the lack of data relating to pharmaceutical treatment and the impacts on fertility. The true costs faced by women and the health system still requires further research.

Scale of delays in diagnosis

It is unknown how many girls and women in Australia live with undiagnosed endometriosis. Many girls and women in Australia are forced to visit their GP and specialists many times before they are finally diagnosed with endo. Further research is required to understand just how many additional GP visits girls and women have until they are finally diagnosed.

What is known is that it can take as long as 12 years[14] before a diagnosis is made, during which time girls and women may be visiting emergency departments, seeing specialists and seeking a variety of pain relief treatments.

Reasons for delays in diagnosis

The reasons for this delay are varied and can be attributed to the requirement of invasive surgery for diagnosis, as well the belief menstrual pain is “normal”. During the period prior to diagnosis, women may move between doctors and in and out of medical care. Many women with chronic gynaecological pain are likely to continue to seek medical assistance, changing doctors in their efforts to find a sympathetic practitioner. A referral to a specialist depends on the GP recognising the pathology, or on a woman convincing her GP that her symptoms are real.[22]

Case study: *13 years to get a diagnosis*

I’ve had endo since I was in grade six and wasn’t diagnosed until I was 35 years old. Before my diagnosis, I have visited my GP multiple times over the years and paid $60 each time. My private health insurance costs me $150 a month but this hasn’t covered all my medical expenses.

Before I was diagnosed, I was sent to two different gynaecologists which cost me around $100 each time. I had an ultrasound which cost me $200, only to be told the pain was in my head and that they wouldn't operate on me. My last doctor put me on the Madeline pill and Provera which costs $30 a month. I have also been referred to a physiotherapist at $60 a month.

My doctor sent me to a chronic pain specialist which costs me $200 per visit. The specialist sent me for an MRI which costed about $500 as it was pelvis and back spine. This specialist then referred me to a pain specialist in Brisbane who charged me $200 per visit. They then sent me to a gynaecologist in Brisbane in 2016 who did my first laparoscopy surgery and diagnosed me with endometriosis.

- Amy S., 2019

4 Direct and indirect costs

Direct healthcare – costs not quantified

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Pharmaceutical treatment

More research is required to understand the scale of pharmaceutical treatments in Australia. This is further complicated by the delays in diagnosis of endometriosis, whereby girls and women silently live with endo undiagnosed and undergo unreported pharmaceutical treatments to alleviate pain.

Pharmaceutical options for women include pain relief and hormonal treatments. Pain relief treatments vary from over the counter medicines such as paracetamol and ibuprofen to prescription medications such as codeine and opioids. Hormonal treatments available include a range of largely contraceptive methods such as the combined oral contraceptive pill, the contraceptive injection (Depo-Provera) and the progestin-only IUD (Mirena).

Typical costs of hormonal treatments in Australia[11]

Many women take contraceptive pills as a way of managing their condition. In the past 20 years, just one pill has been added to Australia's Pharmaceutical Benefits Scheme, (PBS) which subsidises prescription drugs.

It is important to note that not all women respond in the same way to contraceptive medication and may try a variety of contraceptive pills before they find one that works for them.

If provided on a PBS prescription, oral contraceptives typically cost between $6.20 for a concessional consumer and $21 for a general consumer (for a four-month supply).

Unsubsidised oral contraceptives including Yasmin, Marvelon, Yaz, Qlaira and Zoely can cost Australian consumers between $70 and $90 for a three-month supply.

A drug commonly taken by girls and women with endo, Visanne, was developed specifically for the treatment of endo and can cost between $70 and $110 per month.

Infertility

Endo is a common cause of infertility, as severe endo can distort the tubes and ovaries. It may also block the egg's release by causing scar tissue or cysts.

As many as half of women with endo have trouble with fertility[8] and struggle to get pregnant. Some women with endo feel pressured to have children as soon as possible to increase their chances of becoming pregnant. Other women may be ready to have children but can't and as a result have feelings of frustration, hopelessness and may be prone to depression[25].

It is often during investigation to see why women are not falling pregnant that the diagnosis of endometriosis is made.

During pregnancy

Recent studies have shown endo is aligned to a number of risk factors during pregnancy. These include: bleeding after the 24th week of pregnancy, pre-eclampsia (high blood pressure) and a higher chance of delivery by caesarean section.

Further, women with ovarian cysts (endometriomas) who become pregnant using assisted reproductive technologies (ART) have a greater risk of their baby being born before 40 weeks[19].

Effect of pregnancy on endo

Pregnancy does not cure endo, however symptoms may subside during pregnancy. This is a result of higher progesterone levels in the body which can suppress endo. The effects of endo after delivery of a baby are unclear. These effects may only be temporary and many women have a recurrence of the symptoms within a few years[19].

4 Direct and indirect costs
Healthcare related transportation

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Transportation to healthcare costs measures the direct transportation costs that patients incur as a consequence of engaging in health services for the diagnosis and treatment of endo. The total estimated cost of transportation in FY2018 is **$75.1 million**, representing approximately 4.4 million hours spent in transit at an hourly cost of $17/hour. See Page 29 for a detailed methodology on how these figures were estimated.

What's included in transport costs?

Transportation costs are based on an assumption of travel duration costs of $17/hour, in accordance with Australian Transport Assessment and Planning Guidelines. This hourly cost captures costs associated with private vehicle use (e.g. fuel and maintenance) and public transport fares, but does not cover forms of commuting such as taxi or ride-share. This is may lead to an underestimation of hourly transport costs.

$75.1 million

transport cost burden on endo patients on a recurring annual basis

Annual hours in transit

Women with endo spend a cumulative 4.4 million hours in transit travelling to and from healthcare services. This is based on the assumption that women with endo may visit their local GP, undergo surgery at a hospital, drive to the pharmacy to purchase medication or see a specialist up to just four times a year. This figure also assumes travel time on average to be approximately 56 minutes between home and a health service. These estimates are conservative as per capita figures are based off Victorian travel data. It is likely patients in other states and regions where there is comparatively limited access to healthcare may travel much longer distances.

4.4 million hours

spent in transit on a recurring annual basis

Regional Communities

Transportation to healthcare costs disproportionately affect patients living in regional communities, who may have limited access to health services within their local region. Regional patients face higher transportation costs and longer transit durations, and typically have lower salaries than patients living in metropolitan regions.

Case study: *Living in regional NSW and accessing treatment in Sydney*

My daughter has endo and we typically visit a specialist eight times a year in Sydney, which is about a 7.5 hour drive from our home in Moree.

Moree is 1,260km from Sydney and so the fuel alone costs us approximately $1,600 a year (around $200 per round trip).

We spend about a week a year in hospital, which costs us around $3,500 per year. We also typically spend around $3,000 a year on medications, vitamins and pain killers.

In addition to medical expenses, other expenses like meals, accommodation and the occasional taxi costs us around $2,500 per year. We try to stay with friends to keep costs low but sometimes this is unavoidable.

I take at least 3 days off work every trip. For eight trips a year this means I need 24 days leave a year to take my daughter to her medical appointments in Sydney.

- C.D., 2019

4 Direct and indirect costs
Deadweight loss costs

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

The deadweight loss of taxation measures the cost to society of the taxation required for the government to fund the direct healthcare expenses for those diagnosed with endo.

The total estimated deadweight loss cost in FY2018 is **$139.2 million**, representing 27.5%[29] marginal social cost per dollar of government funds targeted at diagnosing and treating endo within the public healthcare system. See Page 30 for a detailed methodology on how these figures were estimated.

What's included in deadweight loss costs?

Deadweight loss is defined as the difference between the imposition of new taxes and the total reduction in output due to these new taxes. As a tax is imposed, it can increase the cost of supplying goods and services, which can also incur price rises for consumers.

In this case, we have defined deadweight loss of taxation as the total reduction in output caused due to taxation required for the government to fund the direct healthcare expenses for those diagnosed with endo.

A 27.5% marginal social cost per dollar multiplied by direct healthcare spending (approximately $506.4 million) was used to estimate this cost.

5

Other impacts

The broader (non-quantifiable impacts of endo)

5 Other impacts

The broader (non-quantifiable) impacts of endo: comorbidities

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

A growing body of research suggests an association between endo and other comorbid and chronic conditions dramatically impacting patients' physical and mental health and wellbeing. Comorbidities are difficult to attribute to endo due to the complexity of symptoms, however women have overwhelmingly given epidemiological evidence of the direct impact they have on their lives.[30]

94 %

of endo patients report one or more comorbidities, including

- Infertility
- Migraines
- Depression

Impact on physical well-being

Patients with endo can experience severe period pain, painful sex, pelvic pain, ovulation pain, irritable bowel, reduced fertility, nausea and lethargy.[38]All patients tend to report some bodily pain and limited physical function as a result of endo. In a 2018 study of 353 females suffering from endo, 66% reported experiencing severe pelvic pain with periods.[20]

The physical pain experienced by women suffering from endo varies greatly between cases, with some women suffering from chronic daily pain including significant impact on bowel, bladder and sexual function.

While pharmacological pain treatment is prescribed to many to help in managing daily life, analgesic side-effects such as dizziness and mood swings as well as resistance to drugs has caused many women to avoid pain treatment.[25]

> ***The psychological damage that [this] has caused me is immense. It's horrible… I feel like I'm not even a woman…I feel like I'm denied some part of being human.***
>
> *- Endo patient[25]*

> ***So many doctors say it's in our heads and is just period pain so it will be very good to have a plan in place to make sure we get the proper care we deserve***
>
> *- Endo patient[13]*

Impact on mental health

Research has demonstrated that the simple fact of being diagnosed with endo may significantly affect women's psychological well-being.

Delayed diagnosis of endo and lack of support and understanding from medical professionals tends to aggravate the psychological hardship for patients. At the time of diagnosis, many women experience a kind of relief in discovering a specific reason for their problems, or found that it was "not in their head" and "they were not mad".[25]

Some research has also shown that awareness of having endo may be associated with negative feelings about being "different", being sick, or being an "incomplete" woman. In extreme cases, patients attribute these feelings to endo interfering with their identity due to possible fertility issues, not being able to do simple daily activities or look after loved ones and simply not feeling like themselves. A negative effect on self-esteem, self-confidence and lack of control of their lives were other reported psychological impacts.[25]

Studies have shown girls and women report they are often compelled to stay in bed and sometimes lose the urge for basic physical needs such as nutrition. Bleeding can cause practical problems and a reluctance to go out. Fatigue amplifies inactivity and functional impairment. This lack of social functionality and engagement can exacerbate unhappiness and anxiety.

5 Other impacts

The broader (non-quantifiable) impacts of endo: General well-being and quality of life

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

The broader impact of endo extends to quality of life and social functioning of the person suffering with endo and their families. The compounding effect of reliance on others, difficulty completing day-to-day tasks and the financial burden impacts the quality of life of patients.

Impact on family and relationships

Women with endo commonly report having difficulty engaging in 'normal' social activities with family, friends, neighbours or groups due to pain and health concerns. patients also report failed relationships, ascribing an inability to share an active life, sexual disability and uncomprehending partners. Many endo patients have reported that intercourse was commonly interrupted by pain. In addition, women with young children reported that endo prevented them from giving the desired level of care to their children [16]. There are also a number of families where parents have become full time carers for their children with endo.

Impact on day-to-day life

Patients report complications completing daily activities such as running, lifting heavy objects, climbing several flights of stairs, bathing or dressing themselves due to impairment of both physical and emotional health. Many women have noted the impact of the chronic condition on their employment, recounting that symptoms led them to take time off work, choose part-time work or give up the chance of promotion due to their perceived reduced productivity.[25]

The financial impact on day-to-day life results from the cost of treatment and pain management (medications, surgery, infertility treatment and complementary therapy) and the decrease in income resulting from working part time or time taken off from work as a direct result of the disease.

> ***Endo is a misunderstood and under researched disease that can be debilitating... Not only is the pain and other issues debilitating, the mental suffering that goes along with it is unfathomable and unreasonable.***
>
> *- Endo patient[13]*

> ***I just feel tired and shattered because you just don't know how to deal with it and you don't know when it's coming back…You just feel like you can't really arrange your life, you are arranging your life around the disease. It controls you even if you don't want it to.***
>
> *- Endo patient[25]*

Household Support

Women suffering from endo have reported an inability to complete everyday household tasks they would otherwise undertake with ease, resulting in a requirement for support from family members or paid labour. A European study in 2009 found that additional help in household activities resulted in a significant financial burden on patients.[31] In addition to the direct costs of these services, the inability to undertake what was once a simple task exacerbates the feelings of hopelessness and loss of identity.[25]

Impact on education

Education was highlighted as a major issue for teenagers suffering from endo, with many taking time off school for as long as an entire term. Students also reported that they found it hard to focus and be as productive as usual when symptoms flared up. Many reported having to study part time, defer university or even leave school to undertake study by correspondence due to the disease. Women were determined not to miss school despite crippling symptoms being reported, relying on taking more medication to overcome the pain.[25]

> ***I was having a lot of time off school and they thought it'd be a good idea to have surgery. I waited about three months for the surgery and then it got to the point where it got really, really bad where I had three weeks straight off from school***
>
> *– Endo patient[25]*

6

Appendix A

Detailed methodology

6 Appendix A
Burden of Disease: Overview

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Burden of Disease

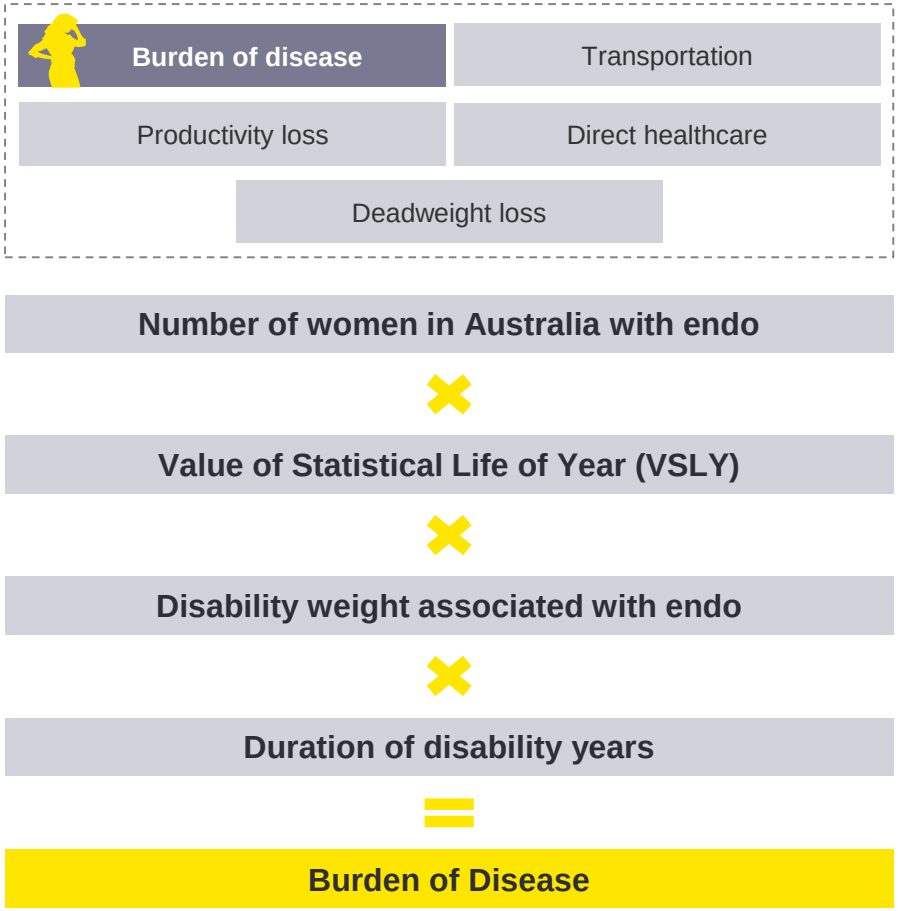
Burden of Disease measures the impact of living with illness and injury and dying prematurely. It is used to quantify the 'burden' of living at a less than optimal level of health. This figure is estimated by multiplying the Value of Statistical Life of Year (VSLY) by a disability weight associated with endo and average duration of disability years.

Data sources for key assumptions

The table below details the assumptions used in estimating Burden of Disease.

Burden of Disease assumptions

Assumption	Source Statistic		Source	Model Input
Number of women in Australia with endo	Number of women in Australia under 51 years of age	6,199,242	Australian Bureau of Statistics, 2017[2]	6,199,242
	Prevalence of endo	10%	Soliman et al, 2016[34]	10%
VSLY	$182,000		Office of Best Practice Regulation, Australian Government, 2014[27]	$200,894 2014 value adjusted for 2017 using CPI Index (RBA)
Disability weight	0.0325		Victorian Department of Human Services, 2001[36]	0.0325
Duration of disability years	1 year		Ibid.	1 year



6 Appendix A
Productivity loss: Overview

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Productivity loss

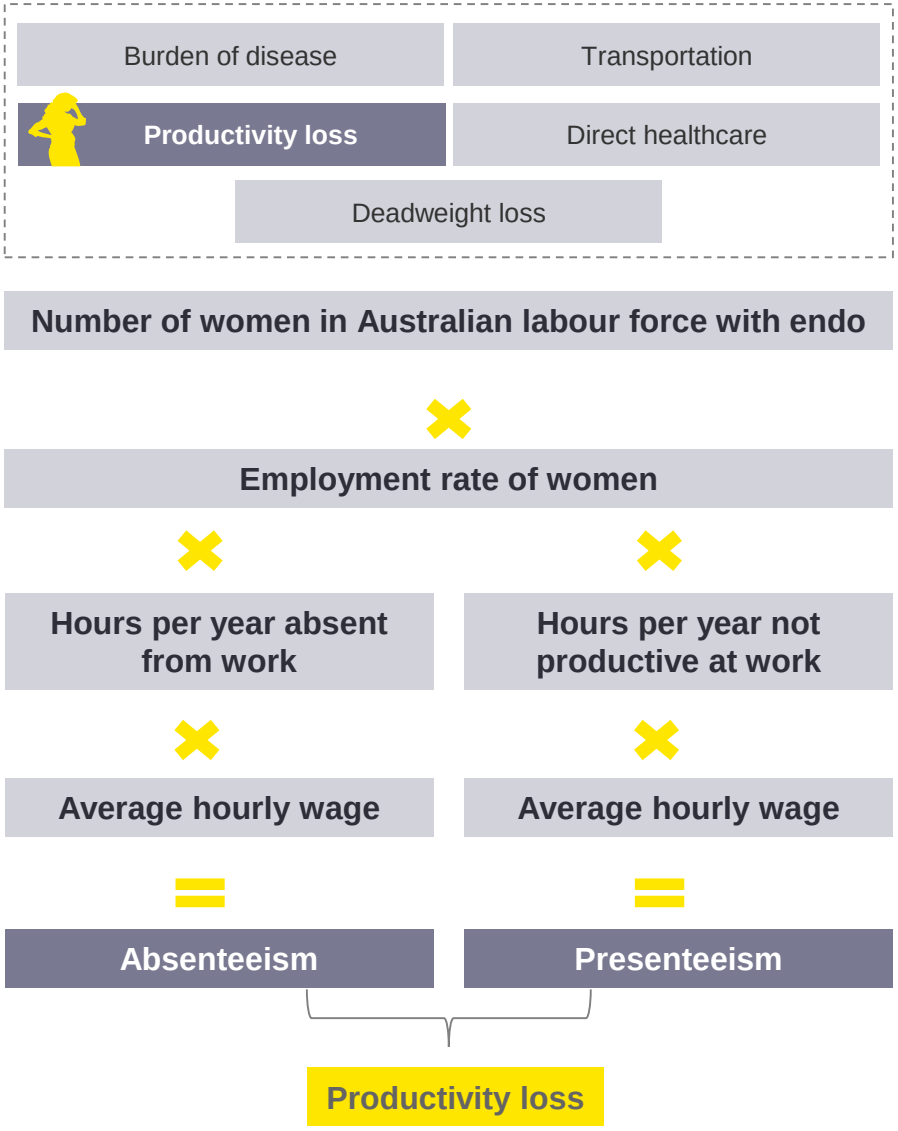
The value of productivity loss has been estimated based on increased levels of absenteeism and presenteeism associated with endo. Absenteeism refers to the practice of regularly staying away from work. Presenteeism refers to working whilst sick which can cause productivity loss, poor health and exhaustion.

Data sources for key assumptions

The table below details the assumptions used in estimating productivity loss.

Productivity loss assumptions

Assumption	Source Statistic		Source	Model Input
Number of women in Australian labour force with endo	Number of women in Australian labour force	6,074,097	Australian Bureau of Statistics, 2018[3]	607,410
	Prevalence of endo	10%	Soliman et al, 2016[34]	
Female employment rate	5.53% (unemployment rate)		Australian Bureau of Statistics, 2018[3]	94.47% (employment rate)
Hours per year absent from work	Ranges from 0.40 to 1.40 (age group dependent)		Soliman, 2017[32]	0.40 to 1.31 Age group dependent, weighted average figures
Hours per year not productive at work	Ranges from 2.80 to 6.60 (age group dependent)		Ibid.	2.80 to 6.21 Age group dependent, weighted average figures
Average hourly wage	Estimated from yearly income for 2015 (latest available) used to calculate hourly wage		Australian Bureau of Statistics, 2018[1]	$13.90 to $32.34 Age group dependent, adjusted for FY2018 using CPI Index, RBA



6 Appendix A
Direct healthcare costs: Overview and frequency of service usage

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Direct healthcare costs

Direct healthcare costs include costs associated with engaging with health services as a result of being diagnosed with endo. This includes hospital admissions, emergency room visits, physician visits, gynaecologist visits and other health specialists, prescriptions and surgeries.

Data sources for key assumptions

The table below details the assumptions used in estimating average service usage within a year.

Direct healthcare assumptions: Annual Service Usage

Assumption	Source	Statistic
Number of women in Australia	Australian Bureau of Statistics, 2017[2]	6,199,242
Prevalence of endo	Soliman et al, 2016[34]	10%
Average emergency room visits per patient	Solimon, 2018[33]	0.05
Average physical office visit per patient	Ibid.	0.79
Average health specialist visit per patient	Ibid.	0.49
Average laparotomies per patient	Australian Department of Human Services, 2018[4]	0.02*
Average laparoscopies per patient	Ibid.	0.06*
Average hysterectomies per patient	Ibid.	0.01*
Average oophorectomies per patient	Ibid.	0.01*

Number of women in Australia with endo

✖

Average service usage within a year (i.e. physician visit or surgery)

✖

Cost per usage

=

Direct healthcare cost

**Assuming that 50-60% of such surgeries recorded in Medicare Statistics Data (MBS) are attributable to endo*

6 Appendix A
Direct healthcare costs: Costs per usage

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Estimating cost per usage: Emergency room and surgeries

Cost per usage was for emergency room visits and surgery costs were estimated using the National Efficient Price (NEP) Determination for public hospital services.

The NEP is a benchmark figure commonly used by governments and healthcare providers as a price signal of the most efficient cost of a health service.

Weights associated with specific healthcare services such as surgeries or emergency room visits are multiplied by the NEP to determine the efficient cost of that specific service.

NEP

×

Service usage weight

=

Cost per usage

Direct healthcare assumptions: Cost per usage

Assumption	Source	Statistic
National Efficient Price (NEP) FY2018	IHPA, 2018[18]	$4,910
Emergency room cost per visit	Ibid.	$544
Laparotomy cost per usage	Ibid.	$6,366
Laparoscopy cost per usage	Ibid.	$6,366
Hysterectomy per usage	Ibid.	$12,248
Hysterectomy with same day oophorectomy cost per usage	Ibid.	$12,248
Oophorectomy cost per usage	Ibid.	$9,965
Other excision / ablation cost per usage	Ibid.	$4,414

6 Appendix A
Direct healthcare costs: Costs per usage

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Estimating cost per usage: Physician and specialist visits

Physician and specialist visit costs were estimated by dividing the total benefits awarded by Medicare across Australia between July 2016 and June 2017 (latest available), by the count of attendances in that time period. Figures were then adjusted for inflation by 2.5% to reflect FY2018 costs.

Direct healthcare assumptions: Service usage and costs

Assumption	Source	Statistic
Physician visits total benefits (Listed as Un-referred Attendances – GP 2016-17)	Australian Department of Human Services, 2018[4]	Total benefits provided $5,930,061,547
Specialist visits total benefits (Listed as Specialist Attendances 2016-17)	Ibid.	Total benefits provided $2,396,569,616
Count of physician visits (2016-17)	Ibid.	129,989,796
Count of specialist visits (2016-17)	Ibid.	31,143,869
Cost per physician visit (2017-18 adjusted)	Ibid.	Estimated as $45.64 per visit
Cost per specialist visit (2017-18 adjusted)	Ibid.	Estimated as $76.98 per visit

Total benefits (funding provided by MBS) across Australia in FY17

÷

Count of visits across Australia in FY17

×

2.5% inflation

=

Cost per usage

6 Appendix A
Healthcare related transport costs: Overview

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Healthcare related transport costs

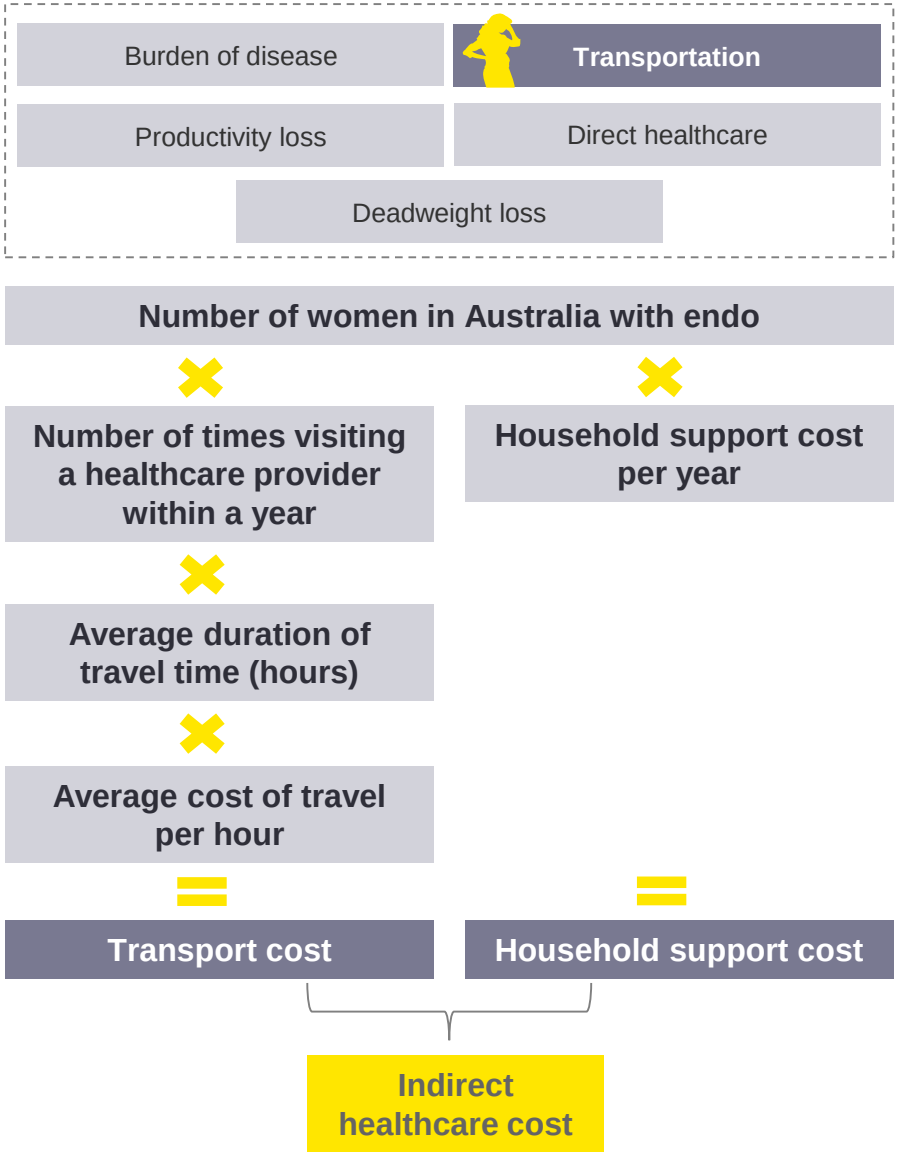
The indirect healthcare costs include costs associated with transportation to and from healthcare services, as well as the additional cost associated with engaging household support.

Data sources for key assumptions

The table below details the assumptions used in estimating healthcare related transport costs.

Direct non-healthcare assumptions

Assumption	Source Statistic		Source	Model Input
Number of women in Australia with endo	Number of women in Australia	6,199,242	Australian Bureau of Statistics, 2017[2]	6,199,242
	Prevalence of endo	10%	Soliman et al, 2016[34]	10%
Number of times visiting a healthcare provider within a year (per patient)	Individual figures for number of emergency room visits, physician office visits, obstetrician & gynaecologist visits and surgeries		Soliman, 2018[33]	1.43 Sum of individual source statistics
Average duration of travel time (hours)	0.93 hours		Victorian Department of Transport, 2018[37]	0.93 hours
Average cost of travel per hour	$15 in 2013		Australian Department of Infrastructure, Regional Development and Cities, 2018[5]	$16.97 (Adjusted 2013 figure to 2018 dollars)



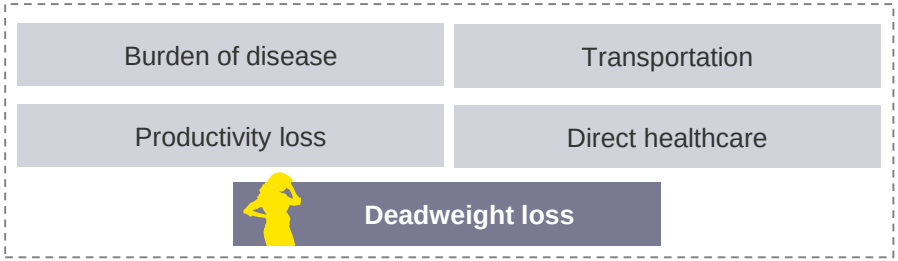
6 Appendix A
Deadweight loss: Overview

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

Deadweight Loss of Taxation

Taxation, in general, creates a discrepancy between the price that producers receive for a good or service and the price that consumers pay for a good or service. In doing so, taxation reduces the quantity of goods and services traded in the market, whilst also raising the price of a good or service. The value of this imposition is referred to as Deadweight Loss.

We have assumed that the government, indirectly, has used taxation revenue to pay for the treatment of endo, which contributes to Deadweight Loss in taxation.



Deadweight loss assumptions

Assumption	Source	Statistic
Deadweight loss factor of taxation	Productivity Commission, 2003[29] De Gruyter, Ford and Stavreski, 2016[12]	27.5% marginal social cost per dollar of government funds

7

Appendix B

References

7 Appendix B
References

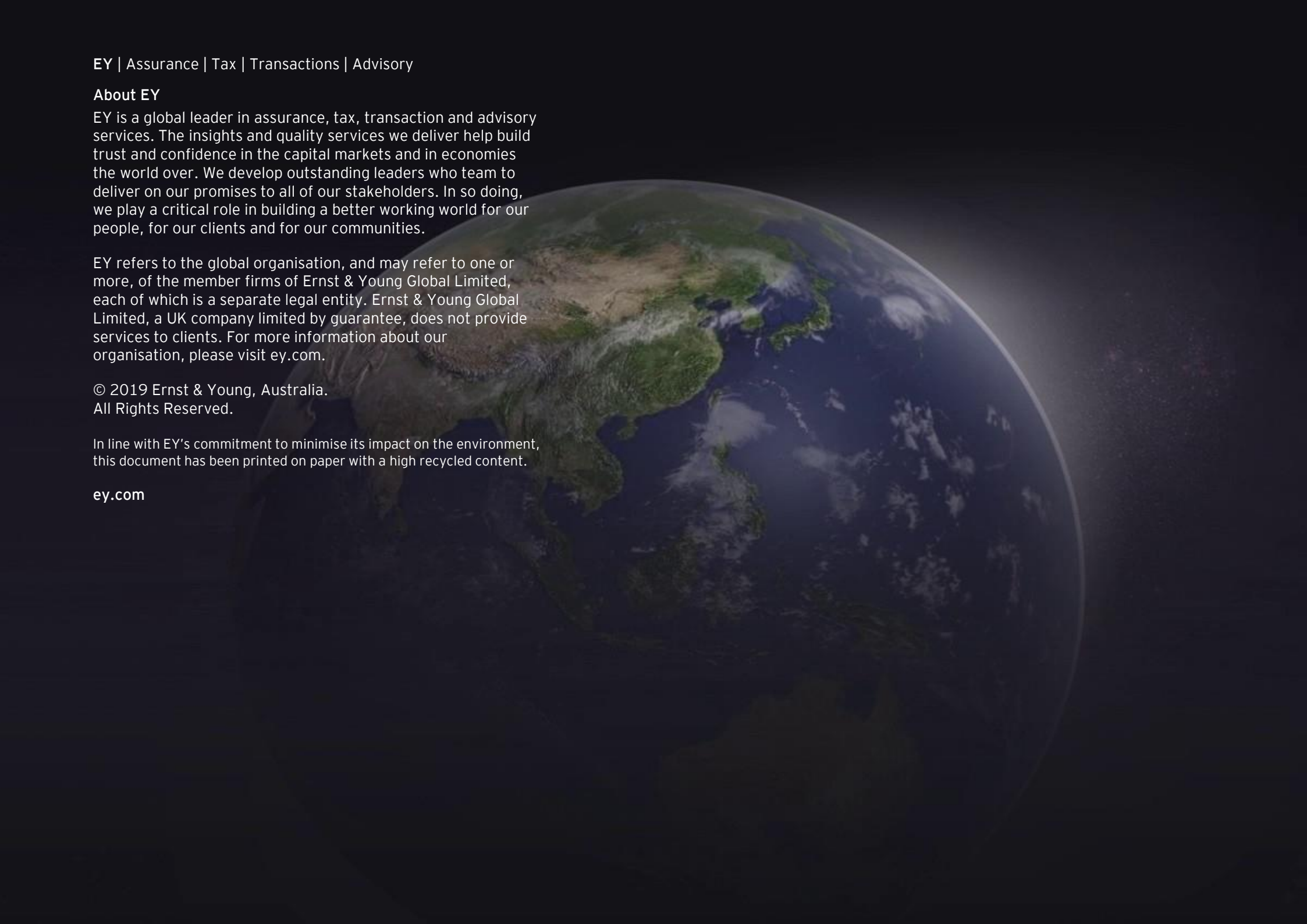
Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

1. Australian Bureau of Statistics. (2018). Estimates of Personal Income for Small Areas, 2011-16, cat. no. 6524.0.55.002, Table 1 Estimates of Personal Income, Employee Incomes by age and sex, 2011-16, Australia, viewed 30 October 2018, http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/6524.0.55.0022011-2016?OpenDocument
2. Australian Bureau of Statistics. (2018). Australian Demographic Statistics, cat. no. 3101.0 Table 4. Estimated Resident Population, States and territories (Number), viewed 30 October 2018, http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3101.0Jun%202018?OpenDocument
3. Australian Bureau of Statistics. (2018). Labour Force, Australia, cat. no. 6202.0, viewed 30 October 2018, http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/6202.0November%202018?OpenDocument
4. Australian Department of Human Services. (2018). Medicare Statistics, viewed 30 October 2018, http://medicarestatistics.humanservices.gov.au/statistics/mbs_group.jsp
5. Australian Department of Infrastructure Regional Development and Cities. (2018). Australian Transport Assessment and Planning Guidelines, viewed 30 October 2018, https://atap.gov.au/
6. Australian Institute of Health and Welfare. (2009). Chronic Disease and Participation in Work. Cat. No. PHE 109. Canberra, viewed 25 March 2019, https://www.aihw.gov.au/getmedia/9a2d0e9b-b55a-4902-af4e-923ba20c788b/cdpw.pdf.aspx?inline=true
7. Bubonya, M., Cobb-Clark, D., and Ribar, D.. (2017). The Bilateral Relationship between Depressive Symptoms and Employment Status. Working paper No. 10/17. Melbourne Institute Working Paper Series, University of Melbourne, viewed 25 March 2019, https://melbourneinstitute.unimelb.edu.au/__data/assets/pdf_file/0010/2308807/wp2017n10.pdf
8. Buletti B, Cocci M, Battistoni S, Borini A. (2010). Endometriosis and infertility. Journal of Assisted Reproduction and Genetics p.441–447.
9. Carer Gateway. (2019). About Carers. Website, viewed 25 March 2019, https://www.carergateway.gov.au/about-carers
10. Chemist Warehouse. (2018). Visanne 2mg Tablets, viewed 30 October 2018, https://www.chemistwarehouse.com.au/buy/76588/visanne-2mg-tablets-2x14
11. Cox, L. (2019). The pill: Lower-income women locked out of new contraceptive ranges. ABC News, viewed 26 March 2019, < https://www.abc.net.au/news/health/2016-09-23/raw-deal-on-the-pill-new-varieties-not-available-on-low-incomes/7868246\
12. De Gruyter E, Ford G, Stavreski B. (2016). Economic and Social Impact of Increasing Uptake of Cardiac Rehabilitation Services - A Cost Benfit Analysis, Heart, Lung and Circulation, Volume 25, Issue 2, pages 175-183.
13. Department of Health, Australian Government. (2018). National Action Plan for Endometriosis. http://www.health.gov.au/internet/main/publishing.nsf/Content/endometriosis
14. Endo Active. (2019). What is Endo?. Website, viewed 27 March 2019, https://endoactive.org.au/what-is-endo/
15. Facchin F, Barbara G, Saita E, Mosconi P, Roberto A, Fedele L, Vercellini P. (2015). Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. Journal of Psychosomatic Obstetrics & Gynaecology.
16. Hållstam A, Stålnacke, B.M., Svensén, C., Löfgren, M. (2018). Living with painful endometriosis – A struggle for coherence. A qualitative study. Sexual & Reproductive Healthcare, 17, 97-102.
17. Hansen K, Kesmodel U, Baldursson E, Schultz R, & Forman A. (2013). The influence of endometriosis-related symptoms on work life and work ability: a study of Danish endometriosis patients in employment. European Journal of Obstetrics & Gynecology and Reproductive Biology, 169, 331-339.
18. IHPA. (2018). National Efficient Price Determination 2017-18, viewed 30 October 2018, https://www.ihpa.gov.au/publications/national-efficient-price-determination-2017-18
19. Jean hailes. (2019). Endometriosis and Fertility. Website, viewed 10 April 2019, https://jeanhailes.org.au/health-a-z/endometriosis/fertility
20. Jenny Sadler Gallagher, Amy D.DI Vasta, Allison F. Vitonis, Vishnudas Sarda, Marc R. Laufer, Stacey A. Missmer (2018) The Impact of Endometriosis on Quality of Life in Adolescents, Journal of Adolescent Health 63, (2018), 766 - 772.

7 Appendix B
References

Dashboard
1 Executive summary
2 Introduction
3 Methodology for estimates
4 Direct and indirect costs
5 Other impacts
6 Appendix A
7 Appendix B

21. Klein S, D'Hooghe T, Meuleman C, Dirksen C, Dunselman G, Simoens S. (2014). What is the societal burden of endometriosis-associated symptoms? A prospective Belgian study. Reproductive BioMedicine Online 28, 116-124.
22. Manderson L, Warren N, Markovic M. (2008). Circuit Breaking: Pathways of Treatment Seeking for Women With Endometriosis in Australia. Qualitative Health Research, 18, 4, 522-534.
23. May C. (2018). Busting the myth that endometriosis is a skinny women's disease. University of Melbourne. https://pursuit.unimelb.edu.au/articles/busting-the-myth-that-endometriosis-is-a-skinny-woman-s-disease
24. Medew, J. (2017) Seeing a specialist. How variations in fees are hidden from patients. The Age, viewed 30 October 2018, https://www.smh.com.au/healthcare/seeing-a-specialist-how-variations-in-fees-are-hidden-from-patients-20170305-gur2kh.html
25. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. (2014). Impact of endometriosis on women's lives: a qualitative study. BMC Women's Health, 14, 123.
26. Nnoaham, K. et al. (2011). Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries, Fertility and Sterility, Volume 96, Issue 2, pages 366-373.
27. Office of Best Practice Regulation, Department of Prime Minister and Cabinet. (2014). Best Practice Regulation Guidance Note Value of Statistical Life, page 3, viewed 30 October 2018, https://www.pmc.gov.au/sites/default/files/publications/Value_of_Statistical_Life_guidance_note.pdf
28. Peters K, Wringley P, Fraser I. (2014). The Cost of Endometriosis in Australia. 12th World Congress on Endometriosis.
29. Productivity Commission. (2003). Evaluation of the Pharmaceutical Industry investment Program, Research Report, Canberra.
30. Shafrir A, Farland L, Shah D, Harris H, Kvaskoff M, Zondervan K, Missmer S. (2018). Risk for and consequences of endometriosis: A critical epidemiologic review. Best Practice Res Clin Obstetrics Gynaecology 51: 1-15;
31. Simoens, S. et al., (2012). The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres, Vol. 27, No. 5, pp 1292-1299.
32. Soliman A., Coyne K., Gries K., Castelli-Haley J., Snabes M., Surrey E., (2017). The Effect of Endometriosis Symptoms on Absenteeism and Presenteeism in the Workplace and at Home, Journal of Managed Care & Specialty Pharmacy, Volume 23(7), pages 745-754
33. Soliman A., Surrey E., Bonafede M., Nelson J., Castelli-Haley J. (2018). Real-World Evaluation of Direct and Indirect Economic Burden Among Endometriosis Patients in the United States, Advances in Therapy, Volume 35, Issue 3, pages 408-423.
34. Soliman A., Yang H., Xiaoyan Du E., Kelly C., Winkel C., (2016). The direct and indirect costs associated with endometriosis: a systematic literature review, Human Reproduction, Volume 31(4), pages 712-722.
35. Treloar, S., O'Connor, D., O'Connor, V., Martin, N. (1999). Genetic influences on endometriosis in an Australian twin sample, Fertility and Sterility, Vol. 71, No. 4.
36. Victorian Department of Human Services. (2005). Victorian Burden of Disease Study: Mortality and morbidity in 2001, page 52, viewed 30 October 2018, https://www2.health.vic.gov.au/about/publications/researchandreports/Victorian-Burden-of-Disease-Study
37. Victorian Department of Transport. (2018). Data and publications, VISTA online data CSV 2012-16, viewed 30 October 2018, https://transport.vic.gov.au/about/data-and-research/vista/vista-data-and-publications
38. Victorian State Government (2019) Better Health,Website viewed 10 April 2019, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/endometriosis



EY | Assurance | Tax | Transactions | Advisory

About EY

EY is a global leader in assurance, tax, transaction and advisory services. The insights and quality services we deliver help build trust and confidence in the capital markets and in economies the world over. We develop outstanding leaders who team to deliver on our promises to all of our stakeholders. In so doing, we play a critical role in building a better working world for our people, for our clients and for our communities.

EY refers to the global organisation, and may refer to one or more, of the member firms of Ernst & Young Global Limited, each of which is a separate legal entity. Ernst & Young Global Limited, a UK company limited by guarantee, does not provide services to clients. For more information about our organisation, please visit ey.com.

© 2019 Ernst & Young, Australia.
All Rights Reserved.

In line with EY's commitment to minimise its impact on the environment, this document has been printed on paper with a high recycled content.

ey.com