Deloitte.

The economic burden of epilepsy in Australia, 2019-2020

Epilepsy Australia

February 2020

Deloitte Access Economics

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Acknowledgements

Deloitte Access Economics acknowledges and thanks Epilepsy Australia for commissioning the report with support from the Australia Epilepsy Community Associations. In particular we would like to thank the following associations for their contribution:

- Epilepsy Foundation
- Epilepsy WA
- Epilepsy Queensland
- Epilepsy Tasmania
- Epilepsy ACT
- Epilepsy Centre South Australia and the Northern Territory

Disclaimer

Deloitte Access Economics completed this work and released it to Epilepsy Australia in June 2019. The data used in the report was current at the time the report was released to Epilepsy Australia.

Glossary

Acronym	Full name
ABC	Aberrant Behaviour Checklist
ABS	Australian Bureau of Statistics
ADHD	Attention deficit hyperactivity disorder
AED	Anti-epileptic drug
AELS	Australian Epilepsy Longitudinal Survey
AIHW	Australian Institute of Health and Welfare
ASD	Autism spectrum disorder
AWE	Average weekly earnings
CDC	Centers for Disease Control and Prevention
DALY	Disability adjusted life year
DRE	Drug resistant epilepsy
DRG	Diagnostic related group
DSP	Disability Support Pension
DSS	Department of Social Services
EEG	Electroencephalogram
GBD	Global burden of disease
GEM	Geriatric evaluation and management
GP	General practitioner
ILAE	International League Against Epilepsy
IPHA	Independent hospital pricing authority
MVA	Motor vehicle accident
MRI	Magnetic resonance imaging
NHMRC	National Health and Medical Research Council
NSA	New start allowance
PAF	Population attributable fraction
QALY	Quality adjusted life year
OR	Odds ratio
OSA	Obstructive sleep apnoea
RBS-R	Repetitive Behaviour Scale-Revised
RR	Relative risk
SDAC	Survey of disability, ageing and carers
SKA	Sickness allowance
SRS	Social Responsiveness Scale
SUDEP	Sudden unexpected death in epilepsy
US	United States
VSLY	Value of statistical life year

Acronym	Full name
WHO	World Health Organisation
YLD	Years lost due to disability
YLL	Years of life lost

Executive summary

In 2019-20, there will be an estimated **142,740** people living with active epilepsy in Australia, costing a total of **$12.3 billion**. The lifetime costs for the estimated **14,603** new cases per year is **$22.2 billion**. Epilepsy doesn't discriminate, being prevalent across gender, age and location.

Background

Epilepsy is a serious neurologic condition that carries with it stigma, psychiatric comorbidities and high economic costs. It is the second most burdensome neurological condition, after dementia, accounting for 14.6% of the burden of disease of all neurological conditions.[1] According to the World Health Organisation (WHO) epilepsy accounts for over 13 million disability-adjusted life years (DALYs) and is responsible for more than 0.5% of the global burden of disease (GBD. While epilepsy is a condition that affects people worldwide, nearly 80% of people living with epilepsy reside in low- and middle-income countries.[2]

The causes of epilepsy are complex and vary depending upon the age at which the first seizure is experienced. Known risk factors include serious head injuries sustained during motor vehicle accidents, trauma or serious falls; strokes or brain haemorrhages; prolonged oxygen deprivation; brain infections and abnormalities; tumours; degenerative conditions such as dementia; and genetic factors. However, in half of all cases, the cause cannot be determined and the individual may never understand why they suffer from the condition.

For those who live with epilepsy, the condition can be debilitating and have serious adverse effects on their personal life, ability to maintain employment, and quality of sleep. It may also pose serious danger to the individual themselves, due to the unpredictable nature of seizure events.

Epilepsy is also associated with a number of comorbidities which can worsen the burden on people living with the condition, and those who provide care to them. In particular, epilepsy has been found to increase the likelihood of an individual experiencing depression and anxiety, fractures, motor vehicle accidents, cardiovascular disease, sleep disorders, neurodevelopmental disorders, and migraines.

Prevalence and incidence

In Australia, there is approximately a 10% population prevalence of individuals who have experienced one seizure during their lifetime.[3] However, as per the International League Against Epilepsy's (ILAE) definition, an individual is only considered to have epilepsy when they experience more than two seizures more than 24 hours apart.[4] By this definition, approximately 3-4% of the Australian population will develop the condition at some stage in their lives.[5]

To estimate the burden of epilepsy in Australia in a given year, only active cases of the condition should be considered. This adjusts the above figure downwards, accounting for cases of epilepsy that have gone into remission. In this case, the Australian Bureau of Statistics (ABS) 2017-18 National

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[1] Australian Institute of Health and Welfare 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. Australian Burden of Disease Study series no. 3. BOD 4. Canberra: AIHW.
[2] World Health Organisation 2019, Epilepsy: A Public Health Imperative - Summary, Geneva, WHO.
[3] Hauser, W.A., Annegers, J. F., & Rocca, W. A. (1996). Descriptive epidemiology of epilepsy: Contributions of population-based studies from Rochester, Minnesota. Mayo Clinic Proceedings, 71(6). 576-586
[4] Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, H., Elger, C. E., Engel, J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D., Lee, B. I., Mathern, G., Moshe, S., Perucca, E., Scheffer, I., Tomson, T., Watanabe, M., & Wiebe, S. (2014). A practical clinical definition of epilepsy. *Epilepsia*, 55(4):475-482.
[5] Epilepsy Australia 2018, *Epilepsy Explained.* Available at: http://www.epilepsyaustralia.net/epilepsy-explained, accessed March 2019

Health Survey (NHS) estimates that 0.6% of Australians of all ages were estimated to be living with the condition.

Due to the complex nature of epilepsy and the stigma that surrounds neurological conditions, accurately estimating the prevalence of epilepsy can be complicated. For example, survey data may be affected by disclosure bias where respondents don't feel comfortable reporting that they are living with epilepsy. It is also possible that some individuals are not aware of their condition, or do not identify as having epilepsy. This may mean that prevalence is higher than estimated. For example, the Centers for Disease Control and Prevention (CDC) estimated that 1.2% of the US population were living with active epilepsy in 2015.[6] If a similar figure is applied to the Australian population, the prevalence of epilepsy may be as high as 250,000. Equally, estimation based on clinical records can be confounded by misdiagnosis, where rates may vary from 4.6% to as high as 30%.

The NHS contains age and gender specific prevalence rates. These were applied to ABS population data to estimate the total prevalence of epilepsy in Australia in 2019-20. It was estimated that a total of 142,740 Australians will be living with active epilepsy during this period, of which 52% are male and 48% are female. By age group, an estimated 19,196 people aged 0-14 are living with epilepsy, 93,987 people aged 15-64 and 29,557 people aged over 65.

Furthermore, the number of new cases of epilepsy annually i.e. the incidence of epilepsy, was also investigated, and based on ratios of incidence to prevalence found in international literature. From this, the average ratio was calculated to be 0.102. This was applied to the NHS prevalence rates for each age group and gender to derive an implied incidence. The total estimated annual incidence of epilepsy is 14,603 new cases. By age group, there are an estimated 1,964 new cases of epilepsy among those aged 0-14, and 9,615 and 3,024 among those aged 15-64 and those over 65 years, respectively.

The report also disaggregated overall prevalence estimates and number of new cases by state and territory (excluding Other Territories as per explanatory note). This is presented in Table i below.

Table i: Prevalence of epilepsy in Australia by jurisdiction, 2019-20

State and territory	Number of active cases (total)	Prevalence (%)	Number of new cases (total)	Incidence (%)
NSW	45,634	0.56	4,669	0.057
VIC	36,775	0.55	3,762	0.057
QLD	28,740	0.56	2,940	0.058
WA	14,727	0.56	1,507	0.057
SA	10,044	0.57	1,028	0.059
TAS	3,110	0.58	318	0.060
ACT	2,344	0.54	240	0.056
NT	1,339	0.53	137	0.054
Other territories^	28	0.60	2	0.043
National	**142,740**	**0.56**	**14,603**	**0.057**

Source: Deloitte Access Economics estimates based on ABS 4364.0.55.001 - National Health Survey: First Results 2017-18 (2018) and ABS 3222.0 - Population projections, Australia, 2017-2066 (2018)
Note: The prevalence differs by state due to the age and gender profiles of the various jurisdictions.

^Note: ABS population projections for Australia include Other Territories, comprising of Christmas Island, Cocos Islands, Jervis Bay Territory and Norfolk Island. While the 28 cases attributable to these territories are included in the Australia-wide estimates, they are not recognised for the purposes of the jurisdiction breakdown.

[6] Zack, M. M., & Kobau, R. (2017). National and state estimates of the numbers of adults and children with active epilepsy - United States, 2015. Morbidity and Mortality Weekly Report, 66(31): 821-825.

Cost of epilepsy in 2019-20

The total annual cost of epilepsy in 2019-20 was $12.3 billion, as summarised in Table ii below. Financial costs associated with epilepsy were estimated to be $4.2 billion for this year. Financial costs include costs related to health care, productivity loss, informal caring, equipment, transportation and deadweight losses.

The largest contributor to financial costs are productivity costs, which account for $2.3 billion of the total (see costs presented in Table ii below). There are also significant costs to the healthcare system related to treatment, which account for $557.1 million of total financial costs. Informal care costs for those with epilepsy were estimated as $438.2 million in 2019-20, while other financial costs, such as equipment and transport, account for $8.6 million and $9.9 million, respectively. Deadweight efficiency losses from government payments and taxation forgone were $821.6 million.

In addition to the financial costs, the burden of the disease, resulting in loss of wellbeing, was estimated to cost Australia $8.2 billion in 2019-20 based on the value of a statistical life year (VSLY) and the disability adjusted life years (DALYs) lost due to the condition.

Table ii: Total annual costs associated with epilepsy, Australia 2019-20

Cost component	Annual cost ($m)
Health system	557.1
Productivity	2,326.6
Informal care	438.2
Equipment	8.6
Transport	9.9
Deadweight losses	821.6
Total financial costs	**4,162.0**
Loss of wellbeing (non-financial)	**8,172.2**
Total costs (financial and non-financial)	**12,334.2**

Source: Deloitte Access Economics estimates

These estimated costs are comparable to many other health conditions, demonstrating the significance of epilepsy in terms of its annual burden in Australia. For example, epilepsy is estimated to impose a greater burden on Australia's health system than prostate cancer ($0.5 billion) and a burden similar to that of lung cancer ($0.6 billion).[7]

Furthermore, the estimated burden of disease of epilepsy is comparable to that of Parkinson's disease. In 2011, it was found that the burden of disease of this common neurological condition was $7.6 billion. This equates to approximately $8.8 billion when inflated to 2019;[8] the equivalent figure for epilepsy is $8.2 billion, as per Table ii.

Lifetime costs of epilepsy

In total, the lifetime cost for the 14,603 new cases of epilepsy in Australia in 2019-20 is $22.2 billion, as summarised in Table iii below. Total lifetime financial costs of new epilepsy cases in Australia in 2019-20 are $7.1 billion, while non-financial costs are $15.1 billion.

[7] Cancer Council 2019, Cancer costs Australian health services over $6 billion a year: new research, available at: https://www.cancercouncil.com.au/media-release/cancer-costs-australian-health-services-6-billion-year-new-research/, accessed April 2019.
[8] Deloitte Access Economics 2011, Living with Parkinson's disease - update, available at: https://www2.deloitte.com/au/en/pages/economics/articles/living-with-parkinsons-disease.html, accessed April 2019.

The largest financial cost component was again the productivity losses stemming from disruption of individuals' productivity. This amounts to an estimated $4.1 billion.

Table iii: Total lifetime costs associated with epilepsy, Australia 2019-20

Cost component	Lifetime cost ($m)
Health system	897.6
Productivity	4,086.6
Informal care	598.8
Equipment	6.7
Transport	20.8
Deadweight losses	1,517.2
Total financial costs	**7,127.7**
Loss of wellbeing (non-financial)	**15,094.7**
Total costs	**22,222.4**

Source: Deloitte Access Economics estimates

1 Epidemiology of epilepsy in Australia

Epilepsy is a serious neurologic condition that carries with it stigma, psychiatric comorbidities and high economic costs. It is defined as a disorder of brain function that takes form of recurring convulsive or non-convulsive seizures.[9] The condition affects people of all ages and, although treatable, often requires lifelong medication. Approximately 30% of all cases will not respond to medication, necessitating surgery or vagus nerve stimulation (VNS) as part of the treatment.[10] This can incur significant costs related to the healthcare system through inpatient and outpatient hospitalisation, research, medication, and out-of-hospital costs.

However, the burden extends beyond these health-related costs. Epilepsy may also reduce employment and lower productivity, and incur deadweight losses associated with reduced income and increased government welfare payments. This, along with the aforementioned health system costs, can place a significant burden on the individual, their carers, and society as a whole.

1.1 Defining epilepsy

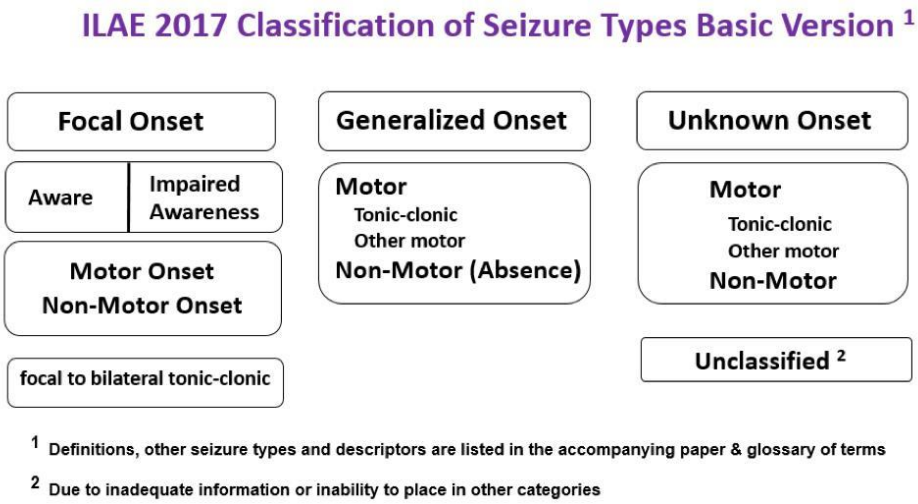
Epilepsy is an umbrella term for a diverse family of disorders that comprise many seizure types and frequency. As such, epilepsy may be defined in several ways. However, the International League Against Epilepsy (ILAE) classifies epilepsy as a disease of the brain that can be defined by the presence of any of the following conditions:[11]

1. At least two unprovoked (or reflex) seizures occurring > 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome.

Around the world, approximately 50 million people are living with the condition, making it one of the most common neurological diseases globally.[12] The aetiology of epilepsy is multifactorial and varies by the individual, ranging from idiopathic to genetic to post-stroke.[13] For people who suffer from epilepsy, seizures can be triggered by infections, excess caffeine or alcohol consumption, and bright lights or drugs, among others.[14] While epilepsy conditions can be categorised into a number of syndromes, they generally fall into two broad categories: primary generalised or focal (shown in Figure 1.1).[15]

[9] Epilepsy Australia 2018, *Epilepsy Explained: What is epilepsy?* Available at: http://www.epilepsyaustralia.net/epilepsy-explained/, accessed March 2019.
[10] Ibid
[11] Fisher, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, H., Elger, C. E., Engel, J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D., Lee, B. I., Mathern, G., Moshe, S., Perucca, E., Scheffer, I., Tomson, T., Watanabe, M., & Wiebe, S. (2014). A practical clinical definition of epilepsy. *Epilepsia*, 55(4):475-482.
[12] World Health Organisation 2019, Epilepsy: A Public Health Imperative - Summary, Geneva, WHO.
[13] Nevalainen, O., Ansakorpi, H., Simola, M., Raitanen, J., Isojarvi, J., Artama, M., & Auvinen, A. (2014). Epilepsy-related clinical characteristics and mortality: a systematic review and meta-analysis. *Neurology*. 82(21):1968-77.
[14] Epilepsy Australia 2018, *Epilepsy Explained*. Available at: http://www.epilepsyaustralia.net/epilepsy-explained/, accessed February 2019.
[15] Ibid

Figure 1.1: Seizure types and classification



Source: Epilepsy Australia, 2019

1.1.2 Focal seizures

As shown in Figure 1.1, focal seizures originate in a specific section of the brain. As such, the effect of the seizure is limited to the parts of the body controlled by that part of the brain. However, this means that symptoms can vary significantly depending on the function that the focal point is associated with or controls. For example, a person may notice involuntary movement or stiffening of a limb, feelings of déjà vu, unpleasant smells or tastes, or sensations in the stomach such as nausea.[16]

People's level of consciousness during focal seizures can also vary. In some cases, the individual will remain completely alert throughout and remember the event, while others can see the individual enter a dyscognitive state. These distinctions between focal seizures were previously termed simple partial seizures and complex partial seizures, respectively. While in the former the individual is likely to be responsive and aware of what is occurring, people suffering the latter are generally unaware, and may appear confused and/or perform strange and repetitive actions.[17]

These seizures typically last no longer than two minutes, however the individual may remain in a state of confusion for minutes or even hours afterwards. The person may also have no memory of the seizure itself or the events immediately before or after the seizure. In certain cases, focal seizures may develop into secondary generalised seizures, a further type of seizure similar to primary generalised but only develop after a focal seizure has occurred. These secondary events tend to occur in more than 30% of people who experience focal seizures.

1.1.3 Primary generalised seizures

In contrast to focal seizures, primary generalised seizures involve the entire brain and, therefore, symptoms can affect the entire body. However, they can take form of either convulsive (motor) or non-convulsive (non-motor), as per Figure 1.1 above. Symptoms associated with primary generalised seizures range from the impairment of the person's responsiveness and awareness, generally lasting no longer than 10 seconds, to full-body convulsions and loss of consciousness lasting many minutes.[18]

At the less severe end of the spectrum are 'absence seizures'. These seizures do not involve a motor response, and may even be difficult to discern from daydreaming. However, they can be particularly disruptive to day-to-day life owing to their sudden onset, the inability to be interrupted, and the frequency at which they can occur.[19] 'Myoclonic seizures' are quite similar to absence seizures in

[16] Epilepsy Foundation 2018. *Types of seizures*. Available at: https://www.epilepsy.com/learn/types-seizures, accessed March 2019.
[17] Ibid.
[18] Ibid.
[19] Ibid.

duration, however they involve a motor response. This takes the form of brief jerks to a muscle or group of muscles, either in a single, isolated event, or repeated many times rapidly.[20]

Other generalised seizure types may elicit a more severe motor response. For example, full-body convulsive seizures are associated with 'atonic', 'tonic' and 'tonic-clonic' seizures, and can vary significantly in terms of duration, level of consciousness and/or type of convulsions. Atonic seizures generally occur during the day and affect the individual's muscle tone, causing them to collapse to the ground. While tonic seizures are similar in nature, they typically occur during sleep and cause the body, arms and/or legs to stiffen. In both cases, the individual tends to retain consciousness, however atonic events carry a heightened level of injury risk due to the time of day at which they occur.[21]

The most serious type of primary generalised seizure is termed 'tonic-clonic'. Each event typically lasts for one to three minutes but can last - either individually or in a series of seizures - over 30 minutes. During these seizures, the individual's body stiffens and they collapse to the ground. While these events generally stop after a few minutes, confusion and drowsiness can last for a number of hours, making this the most debilitating form of epilepsy.[22]

Tonic-clonic seizures are also the most likely to cause serious harm to the individual. While they generally last one the three minutes, events lasting longer than five minutes are not uncommon and require immediate medical attention. The most severe cases (e.g. lasting longer than 5 minutes) indicate a dangerous condition called status epilepticus, a condition that requires emergency attention in hospital.[23] While the seizure itself is unlikely to cause serious harm to the individual, injuries can occur while collapsing and also due to the person biting their tongue or cheek. Furthermore, these seizures are a common risk factor for sudden unexplained death in epilepsy (SUDEP), which is discussed further in Section 2.3.

1.1.4 Risk factors of epilepsy

Epilepsy is a common neurological condition that can develop at any stage in the life course, irrespective of gender or ethnicity. In fact, research suggests that approximately 3-4% of the Australian population will develop epilepsy at some stage in their lives.[24] The causes of epilepsy are complex and vary depending upon the age at which the first seizure is experienced. However, in half of all cases, the cause cannot be determined and the individual may never understand why they suffer from the condition.[25]

Notwithstanding this uncertainty surrounding many cases, several known risk factors do exist. These include:[26]

- Head injury such as in a car accident, trauma or serious fall.
- Stroke or brain haemorrhage.
- A lack of oxygen to the brain for a prolonged period (such as in birth trauma, cardiac arrest, drowning, drug overdose).
- Brain infections (for example, meningitis, encephalitis or brain abscess).
- Brain abnormalities or malformations, particularly during childhood.
- Brain tumours, an uncommon cause in children but more common in adults and the elderly.
- Genetic factors, such as having a parent with epilepsy.
- Degenerative conditions affecting the brain (such as dementia or Alzheimer's disease).

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[20] Epilepsy Foundation 2018, *Myoclonic seizures*. Available at: https://www.epilepsy.com/learn/types-seizures/myoclonic-seizures, accessed March 2019.
[21] Epilepsy Australia 2018, *Epilepsy explained*. Available at: http://www.epilepsyaustralia.net/epilepsy-explained/, accessed March 2019.
[22] Ibid.
[23] Epilepsy Foundation 2018, *Tonic-clonic seizures*. Available at: https://www.epilepsy.com/learn/types-seizures/tonic-clonic-seizures, accessed March 2019
[24] Epilepsy Australia 2018, *Epilepsy explained: Who gets epilepsy?* Available at: http://www.epilepsyaustralia.net/epilepsy-explained/, accessed March 2019.
[25] Ibid.
[26] Ibid.

1.1.5 Risk factors for seizures

In addition to the risk factors for having a first seizure and being diagnosed with epilepsy, there are a range of factors associated with seizure occurrence in people who are epileptic. For these individuals who already suffer from epilepsy, triggers may include:[27]

- Alcohol consumption, due to interaction with medications.
- Dietary factors, such as high levels of caffeine.
- Infections or illness, particularly in children.
- Sleep deprivation, especially due to large fluctuations in one's sleep pattern.
- Medication adherence, or lack thereof.
- Use of other medications or recreational drugs.
- Photosensitivity, severe temperature changes and high stress levels for certain individuals.

It has also been noted in the literature that Indigenous Australians face disproportionately high rates of seizure-related hospital admissions compared to non-indigenous.[28] Between 1998 and 2004, the rate of hospitalisation related to seizures for Indigenous Australians was five times more than the non-Indigenous rate. Whilst this is not a risk factor in itself, it likely reflects the health inequalities experienced by Indigenous Australians which results in poor seizure control for those living with epilepsy.

1.2 Epilepsy treatment

Treatment of epilepsy is dependent on a range of factors, foremost of which is how the condition is classified. In most cases, antiepileptic medication is used, however the choice of which medication is dependent upon severity, frequency, side effects and interactions, and other individual characteristics such as age or gender. Nonetheless, 60-70% of people diagnosed with epilepsy will gain seizure control through medication alone within a year.[29] After two to five years of successful adherence and being seizure-free, medication can be withdrawn in about 70% of children and 60% of adults without later relapse.[30]

However, in some cases epilepsy may be medication-resistant, necessitating the use of alternative treatments. This may involve surgery, stimulation of the vagus nerve, or, particularly in children, the ketogenic diet may be recommended.[31] Surgery and vagus nerve stimulation are only considered in cases when medication has failed but can be highly effective at controlling seizures in many cases. For example, surgery has a high success rate for seizures that are found to be caused by abnormal brain tissue. Vagus nerve stimulation is generally only considered if the condition has been unresponsive to medication and other surgical options have been ruled out. This procedure involves the implant of a stimulator attached to the vagus nerve to deliver intermittent but frequent pulses to regulate the activity of the vagus nerve.[32]

In other situations where seizure control is not satisfactory through medication, particularly involving children, a ketogenic diet may be considered to control seizures. The mechanisms through which this operates are not yet fully understood, however it has proved effective in many cases. It has proven to elicit the most beneficial responses from children with mixed myoclonic seizure disorders, however there have also been reports of success in adults and with other types of epilepsy.[33]

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[27] Epilepsy Australia 2018, *Epilepsy Explained*. Available at: http://www.epilepsyaustralia.net/epilepsy-explained/, accessed February 2019.
[28] Plummer, C., Cook, M. J., Anderson, I., & D'Souza, W. (2014). Australia's seizure divide - indigenous versus non-indigenous seizure hospitalisation. *Epilepsy & Behaviour*, 31: 363-368.
[29] Epilepsy Australia 2018, *Epilepsy Treatment*. Available at: http://www.epilepsyaustralia.net/epilepsy-treatment/, accessed March 2019.
[30] World Health Organisation 2019, *Epilepsy: Treatment*. Available at: https://www.who.int/news-room/fact-sheets/detail/epilepsy, accessed March 2019.
[31] Epilepsy Australia 2018, *Epilepsy Treatment*. Available at: http://www.epilepsyaustralia.net/epilepsy-treatment/, accessed March 2019.
[32] Ibid
[33] Ibid

2 Prevalence and incidence of epilepsy

2.1 Prevalence of epilepsy

The prevalence of epilepsy refers to the total number of people living with the active condition in a given time period. Active epilepsy is defined as cases in which the individual is experiencing ongoing seizures or requires ongoing treatment through medication or alternative methods.[34]

In Australia, there is approximately a 10% population prevalence of individuals who have experienced one seizure during their lifetime. [35] However, by definition, a case is only considered epilepsy when more than two seizures occur more than 24 hours apart. In these terms, around 3-4% of the population will develop the condition at some point in their lives.[36] Refining further to only consider those whose condition is active at any given time results in a population prevalence of approximately 6 persons per 1,000 population in Australia, as estimated by the Australian Bureau of Statistics (ABS).[37]

There is a significant body of literature that validates these Australian findings. For example, it was found that the prevalence of active epilepsy in high-income countries is generally estimated to be between five and eight per 1,000 persons.[38] In comparison, low and middle-income countries are typically estimated to experience a prevalence of approximately 10 persons per 1,000 population.[39] It is suggested that this between-country heterogeneity is reflective of economic development and, specifically, regional risk of infections, differences in antenatal and perinatal care, and overall quality of and access to healthcare.[40] There are also notable differences observed throughout the life course, and some tenuous evidence of gender based heterogeneity.[41]

When estimating the prevalence of epilepsy, it should also be noted that there is the possibility of over or underreporting of the condition. This may occur for a number of reasons, including the following:

- As prevalence estimates are often based on self-reported data, subsets of the population who do not fully understanding their condition may incorrectly state that they have the condition without diagnosis, or vice versa.
- It may also be the case that some individuals do not feel comfortable reporting their condition when responding to surveys due to the social stigma surrounding neurological conditions. This 'disclosure bias' may mean true prevalence is higher than estimated. For example, the Centers for Disease Control and Prevention (CDC) estimated that 1.2% of the US population were living with active epilepsy in 2015.[42] If a similar figure is applied to the Australian population, the prevalence of epilepsy may be as high as 250,000.

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[34] World Health Organisation 2019, *Epilepsy: Rates of Disease*. Available at: https://www.who.int/news-room/fact-sheets/detail/epilepsy, accessed March 2019.
[35] Hauser, W. A., Annegers, J. F., & Rocca, W. A. (1996). Descriptive epidemiology of epilepsy: Contributions of population-based studies from Rochester, Minnesota. *Mayo Clinic Proceedings*, 71(6):576-586.
[36] Bell, G. S., Neligan, A., & Sander, A. W. (2014). An unknown quantity: The worldwide prevalence of epilepsy. *Epilepsia*, 55(7):958-962.
[37] Australian Bureau of Statistics 2018, National Health Survey: First Results, 2017-18. Cat. no. 4364.0.55.001. Canberra, Australia.
[38] Kotsopoulos, I. A., Van Merode, T., Kessels, F. G., De Krom, M. C., & Knottnerus, J. A. (2002). Systematic review and meta-analysis of incidence studies of epilepsy and unprovoked seizures. *Epilepsia*, 43(11):1402-1409.
[39] Moshe, S. L., Perucca, E., Ryvlin, P., & Tomson, T. (2014). Epilepsy: new advances. *The Lancet*, 385(9971):884-898.
[40] Fiest, K. M., Sauro, K. M., Wiebe, S., Patten, S. B., Kwon, C., Dykeman, J., Pringsheim, T., Lorenzetti, D. L., & Jette, N. (2017). Prevalence and incidence of epilepsy: A systematic review and meta-analysis of international studies. *Neurology*, 88(3): 296-303.
[41] McHugh, J. C., & Delanty, N. (2008). Epidemiology and classification of epilepsy: gender comparisons. *International Review of Neurobiology*, 83: 11-26.
[42] Zack, M. M., & Kobau, R. (2017). National and state estimates of the numbers of adults and children with active epilepsy - United States, 2015. *Morbidity and Mortality Weekly Report*, 66(31): 821-825.

- Misdiagnosis of epilepsy by clinicians can also occur. Reported misdiagnosis rates vary substantially with estimates drawn from international studies ranging between 4.6% and 30%.[43] Two studies in the United Kingdom purposely designed to assess the prevalence of misdiagnosis within the community found that epilepsy was misdiagnosed between 16% and 23% of cases.[44,45] As such, it is also possible that prevalence rates of epilepsy are over-reported.

Overall, the literature suggests that epilepsy is active in between 6 and 7.5 persons per 1,000 population in Australia.[46] This figure is consistent with the estimated range for high-income countries in the literature and more recent estimates released by the ABS, which indicate that there is an overall population prevalence of active epilepsy of 0.6%.[47] These prevalence rates would suggest that approximately 150,000 Australians are living with active epilepsy. For the modelling in this report, we develop a more precise estimate using the methods outlined below.

Estimates produced for this report by Deloitte Access Economics are based on National Health Survey (NHS) data published by the ABS.[48] The NHS was conducted from a sample of approximately 21,300 people in 16,400 private dwellings across Australia between July 2017 and June 2018, and contains a component which asks whether respondents have epilepsy. These NHS prevalence rate estimates were applied to ABS population projection data for June 2019 to estimate the total prevalence of epilepsy.

Our estimates indicate that 142,740 people are living with active epilepsy in Australia. This estimate may be conservative if epilepsy is significantly underreported in self-reported data, however it is also consistent with a number of existing studies. Table 2.1 below presents this prevalence figure, disaggregated by applying gender and age-specific rates reported in the NHS.

Table 2.1: Prevalence of epilepsy in Australia by age and gender, 2019-20

Age group	Prevalence rate (%, males)	Prevalence (total, males)	Prevalence rate (%, females)	Prevalence (total, females)	Total
0-14	0.4	9,854	0.4	9,342	**19,196**
15-24	0.4	6,686	0.4	6,369	**13,055**
25-34	0.3	5,708	0.1	1,915	**7,623**
35-44	0.5	8,419	0.8	13,618	**22,037**
45-54	1.0	15,764	1.0	16,386	**32,150**
55-64	0.6	8,610	0.7	10,513	**19,123**
65+	1.0	18,853	0.5	10,704	**29,557**
Total	**0.59**	**73,893**	**0.54**	**68,847**	**142,740**

Source: Deloitte Access Economics estimates based on ABS 4364.0.55.001 - National Health Survey: First Results 2017-18 (2018) and ABS 3222.0 - Population projections, Australia, 2017-2066 (2018).
Note: Figures may not sum to total due to rounding.

For the purposes of this report, it is assumed that prevalence rates by age and gender are constant across states and territories. However, due to differences in population age and gender distributions, epilepsy is imposing a slightly greater burden in some jurisdictions than in others. Overall, prevalence is very similar across states and territories, however Tasmania is estimated to have the highest rate

[43] Chowdhury, F. A., Nashef, L., & Elwes, R. D. C. (2008). Misdiagnosis in epilepsy: a review and recognition of diagnostic uncertainty. *European Journal of Neurology*, 15(10): 1034-1042.
[44] Scheepers, B., Clough, P. & Pickles, C. (1998). The misdiagnosis of epilepsy: findings of a population study. *Seizure*, 7(5): 403-406.
[45] Leach, J. P., Lauder, R., Nicolson, A., & Smith, D. F. (2005) Epilepsy in the UK: misdiagnosis, mistreatment, and undertreatment?: the Wrexham area epilepsy project. *Seizure*, 14(7): 514–20.
[46] D'Souza, W. J., Fryer, J. L., Quinn, S. J., Taylor, B. V., Ficker, D. M., O'Brien, T. J., Pearce, N. E., & Cook, M. J. (2007). The Tasmanian Epilepsy Register - A community-based cohort: background and methodology for patient recruitment from the Australia national prescription database. *Neuroepidemiology*, 29:255-263.
[47] Australian Bureau of Statistics 2018, National Health Survey: First Results, 2017-18. Cat. no. 4364.0.55.001. Canberra, Australia.
[48] Ibid.

(0.59%) while the Northern Territory has the lowest (0.53%). Prevalence by state and territory is presented in Table 2.2 below.

Table 2.2: Prevalence of epilepsy in Australia by jurisdiction, 2019-20

Jurisdiction	Share of total population (%)	Implied prevalence
NSW	31.99	45,634
VIC	25.99	36,775
QLD	20.05	28,740
WA	10.32	14,727
SA	6.87	10,044
TAS	2.09	3,110
ACT	1.69	2,344
NT	0.99	1,339
^Other territories	0.02	28
Total	**100**	**142,740**

Source: Deloitte Access Economics estimates based on ABS data (2018). Note: The prevalence differs by state due to the age and gender profiles of the various jurisdictions.

^Note: ABS population projections for Australia include Other Territories, comprising of Christmas Island, Cocos Islands, Jervis Bay Territory and Norfolk Island. While the 28 cases attributable to these territories are included in the Australia-wide estimates, they are not recognised for the purposes of the jurisdiction breakdown.

2.2 Incidence of epilepsy

The incidence of epilepsy refers to the total number of cases first diagnosed or reported in a given year. For the purposes of this report, our analysis estimated the total number of cases first diagnosed or reported in the year 2019-20, and the associated lifetime cost. An underlying assumption is that each new case of epilepsy is a lifelong condition, with an average life expectancy of 82 years for people who develop the condition, similar to the overall average life expectation in Australia.[49]

The observed incidence of epilepsy has been reported to vary in a manner similar to prevalence. Specifically, it is estimated that the annual incidence is 45 persons per 100,000 population in high-income countries and 82 in low and middle-income countries.[50] For adults, which is generally defined in the literature to be those aged 20-64, incidence has been estimated as being between 30 and 35 per 100,000 persons per year.[51] [52]

For the purposes of this report, incidence rates for epilepsy in Australia were derived from ratios of incidence to prevalence rates found in the international literature. The incidence and prevalence rates reported in each of these studies are outlined in Table 2.3.

[49] The onset of epilepsy was assumed to occur at the midpoint of each age group considered in the economic modelling section of this report.
[50] Ngugi, A. K., Kariuki, S. M., Bottomley, C., Kleinschmidt, I., Sander, J. W., & Newton, C. R. (2011). Incidence of epilepsy: a systematic review and meta-analysis. *Neurology*, 77:1005-1012.
[51] Ibid.
[52] Kotsopoulos, I. A., Van Merode, T., Kessels, F. G., De Krom, M. C., & Knottnerus, J. A. (2002). Systematic review and meta-analysis of incidence studies of epilepsy and unprovoked seizures. *Epilepsia*, 43(11):1402-1409.

Table 2.3: International literature for incidence and prevalence of epilepsy

Study	Prevalence (per 1,000 persons)	Incidence (per 100,000 persons)	Ratio of incidence to prevalence (per 1,000 persons)
Fiest et al. (2017)	6.38	61.44	0.096
Helmers et al. (2015)	5.0	64.5	0.129
Christensen et al. (2007)	5.7	68.8	0.121
Hirtz et al. (2007)	7.1	48	0.068
Olafsson et al. (1996, 1999)	4.8	47	0.098
Average	**5.8**	**57.95**	**0.1023**

Source: Deloitte Access Economics estimates based on Fiest et al. (2017), Helmers et al. (2015), Christensen et al. (2007), Hirtz et al. (2007), Olafsson et al. (1996, 1999), ABS 4364.0.55.001 - National Health Survey: First Results, 2017-18 (2018) and ABS 3222.0 - Population projections, Australia (2018).

The ratios were calculated as:[53]

$$Ratio = \frac{Incidence}{Prevalence \times 100}$$

From this, the average ratio was calculated to be 0.1023. This was applied to the age and gender specific prevalence rates to derive the corresponding implied incidence rates. These rates are reported in Table 2.4 below.

Table 2.4: Estimated incidence of epilepsy by age and gender in Australia, 2019-20

Age group	Prevalence (%, males)	Implied incidence (%, males)	Implied incidence (total, males)	Prevalence (%, females)	Implied incidence (%, females)	Implied incidence (total, females)	Incidence (total)
0-14	0.40	0.04	1,008	0.40	0.04	956	**1,964**
15-24	0.40	0.04	684	0.40	0.04	652	**1,336**
25-34	0.30	0.03	584	0.10	0.01	196	**780**
35-44	0.50	0.05	861	0.80	0.08	1,393	**2,254**
45-54	1.00	0.10	1,613	1.00	0.10	1,676	**3,289**
55-64	0.60	0.06	881	0.70	0.07	1,076	**1,956**
65+	1.00	0.10	1,929	0.50	0.05	1,095	**3,024**
Total	**0.59**	**0.06**	**7,560**	**0.54**	**0.05**	**7,043**	**14,603**

Source: Deloitte Access Economics estimates based on Feist et al. (2017), Helmers et al. (2015), Christensen et al. (2007), Hirtz et al. (2007), Olafsson et al. (1996, 1999), and ABS 4364.0.55.001 - National Health Survey: First Results, 2017-18.

2.3 Epilepsy-related mortality

People living with epilepsy have a heightened risk of premature death. This can be due to the condition itself, but also one or more associated comorbidities. In fact, it is suggested that people living with epilepsy may have a mortality risk that is two to three times higher than the general population.[54] Moreover, the risk of sudden and unexpected death is approximately 24 times higher.[55]

[53] Prevalence is multiplied 100 as reporting conventions in the literature sees prevalence report per 1,000 persons, while incidence is reported per 100,000 persons.
[54] Gaitatzis, A., & Sander, J. W. (2003). The mortality of epilepsy revisited. *Epileptic Discord*, 6:3-13.
[55] Ficker, D. M., So, E. L., Shen, W. K., Annegers, J. F., O'Brien, P. C., & Cascino, G. D. (1998). Population-based study of the incidence of sudden unexplained death in epilepsy. *Neurology*, 51(5):1270-1274.

The major causes of death for people with epilepsy include:

- accidents
- drowning
- status epilepticus
- suicide
- sudden unexpected death in epilepsy (SUDEP).

The most common cause of epilepsy-related death is SUDEP. This condition is defined as a sudden and unexpected non-traumatic or non-drowning-related death in a patient with epilepsy that may or may not be related to a recent seizure.[56] Overall, the incidence of SUDEP in the general epilepsy population has been reported to be as high as 1.2 per 1000 persons per year in the general epilepsy population.[57] Based on the estimated 142,740 people living with epilepsy in Australia, this would equate to approximately 171 SUDEP-related deaths per year across the general epilepsy population. These deaths occur in otherwise healthy individuals with epilepsy, generally during or immediately following a tonic-clonic seizure.

Between 2007 and 2017, the average number of deaths in Australia attributable to epilepsy was 284 per year according to the ABS, however AIHW provides a slightly higher estimate of 322 in 2015.[58,59] Assuming a SUDEP rate of 1.2 per 1000 persons, there are more than a 100 epilepsy-related deaths in Australia per year not attributable to SUDEP. Other factors such as workplace or motor vehicle accidents, drowning, suicide and status epilepticus account for the majority of the remaining deaths. In particular, status epilepticus has been responsible for an average of 22, or 7.6%, of the epilepsy-related deaths per year between 2007 and 2017.[60] The reported number deaths attributable to epilepsy is likely to be underestimated as the number of deaths reflect cases where there is strong evidence linking the death to epilepsy.

According to AIHW, there were 322 deaths attributable to epilepsy in 2015. The AIHW mortality rate of 322 was used in the modelling of the report as the figure is disaggregated by age and gender.[61] The figure was inflated to 2019-20 using an implied mortality rate and the estimated prevalence of epilepsy in 2019-20, giving a total number of deaths attributable to epilepsy of 342 in 2019-20.

[56] Nashef, L. (1997). Sudden unexpected death in epilepsy: terminology and definitions. *Epilepsia*, 38(11):6-8.
[57] Tomson, T., Nashef, L., & Ryvlin, P. (2008). Sudden unexpected death in epilepsy: current knowledge and future directions. *The Lancet Neurology*, 7(11):1021-1031.
[58] Australian Bureau of Statistics (ABS). Causes of Death, Australia, 2017. Cat. no. 3303.0. ABS, Canberra, 2018.
[59] AIHW 2018, Australia Burden of Disease Study 2015: Fatal burden preliminary estimates.
[60] Ibid.
[61] Ibid.

3 Health costs of epilepsy

This section estimates the health care costs of epilepsy in Australia. Estimates of direct health system costs on epilepsy were based on several dataset including the Australian Institute of Health and Welfare (AIHW) and the Independent Hospital Pricing Authority (IHPA). The study follows a 'bottom-up approach' to estimate expenditure. The health care costs include:

- hospital inpatients and outpatients
- primary medical care by general practitioners
- pathology and imaging
- pharmaceuticals
- research

3.1 Hospital inpatient costs

The total cost of hospitalisation for epilepsy was estimated by multiplying the number of separations for epilepsy by an estimated average cost of hospitalisation. The number of hospitalisations was based on separation statistics from the IHPA's National Hospital Cost Data Collection[62] and the AIHW's Health Expenditure data[63].

AIHW data provides the number of separations in public and private hospitals for acute, sub-acute and non-acute admissions. The number of separations where the principal diagnosis is epilepsy was estimated using the number of separations where the Diagnostic Related Group (DRG) was seizures with and without catastrophic consequences (B76A or B76B respectively). As these DRGs also contain admissions for fits, seizures and convulsions not specified as epilepsy, it is assumed that 50% of all hospital separations for seizures have epilepsy as principal diagnosis. This is a conservative assumption and is based on the ratio outlined in 1.1, that approximately 60% of people who have one seizure go on to have more seizures, which would be diagnosed as epilepsy[64]. In 2016-17, 0.55% of all hospital separations were attributed to major and minor seizures.[65] It is assumed that half of these separations can be attributed to epilepsy.

Table 3.1 below summarises the estimated number of acute, sub-acute and non-acute admissions for 2019-20 and the associated costs. As the separations are from 2016-17, an annual growth rate of 4.1% was applied to estimate the 2019-20 separations. This growth rate is based on the historic five year growth of total hospital separations. Separations by jurisdiction is summarised in Appendix A.

The average costs per weighted acute, sub-acute and non-acutes separations of $5,444 and $13,997 respectively are sourced from IHPA data, which provides costs by DRG in public hospitals. It is assumed that the average cost rate is the same for both private and public hospitals. The average costs are weighted to consider the complexity of each jurisdiction's work profile. This allows average costs to be compared between jurisdictions (see Appendix A for average cost by jurisdiction). The average costs were inflated to 2019-20 values by using the health inflation rate of 1.7 per cent, based on AIHW hospital expenditure data[66].

The acute separation cost components included costs associated with hospital ward, non-clinical, pathology, imaging, allied health, pharmaceuticals, critical care, operating rooms, admittance through the emergency department, supplies and others. Sub-acute and non-acute care included geriatric evaluation and management (GEM), maintenance, palliative care, psychogeriatric and

[62] Independent Hospital Pricing Authority, 2019, National Hospital Cost Data Collection Report, Round 21 (Financial year 2016-17), available from: https://www.ihpa.gov.au/publications/national-hospital-cost-data-collection-independent-financial-review-round-21-financial
[63] Australian Institute of Health and Welfare, 2018, Health Expenditure Australia 2016-17, available from: https://www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure-australia-2016-17/data
[64] Epilepsy Australia, available from: http://www.epilepsyaustralia.net/epilepsy-explained/
[65] Ibid
[66] Australian Institute of Health and Welfare, 2018, Health Expenditure Australia 2016-17, available from: https://www.aihw.gov.au/getmedia/e8d37b7d-2b52-4662-a85f-01eb176f6844/aihw-hwe-74.pdf.aspx?inline=true

rehabilitation. The total estimated hospital inpatient costs related to epilepsy for 2019-20 is $199.4 million.

Table 3.1: Estimated hospitalisation costs, 2019-20

Component	Acute	Sub-acute and non-acute	Total separations
Number of separations (number)	31,194	1,804	32,998
Average cost per weighted separation ($), 2019-20 prices	5,444	13,997	-
Total costs ($ million), 2019-20 prices	**169.8**	**29.6**	**199.4**

Source: IPHA (2019) and AIHW (2018). A growth rate of 4.1% annually is applied to project the number of separations in 2016-17 to 2019-20. A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

3.2 Hospital outpatient costs

Outpatient, or non-admitted events relate to services provided in an outpatient clinic. Services typically include diagnostic testing, specialised care for complex epilepsy patients, surgical programs and telehealth services. The number of outpatient events were sourced from IPHA data, which provides annual non-admitted events and average costs, by jurisdiction. Similar to inpatient costs, the number of events related to epilepsy was estimated by applying the share of epilepsy related separations to the total number of events. This results in an estimated 96,838 events related to epilepsy per year. Total estimated outpatient costs related to epilepsy for 2019-20 were estimated to be $31.5 million.

Table 3.2: Estimated outpatient costs related to epilepsy, 2019-20

Component	Estimates
Events related to epilepsy (number)	96,838
Average cost ($), 2019-20 prices	325
Total cost ($ million), 2019-20 prices	**31.5**

Source: IPHA (2019) and AIHW (2018). A growth rate of 4.1% annually is applied to project the number of events in 2016-17 to 2019-20. A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

Note: Non-admitted events was only available for public hospitals. A ratio of 0.7 was applied to estimate the number of non-admitted events at private hospitals. This was based on the ratio of public to private hospital separations, IPHA (2019)[67].

3.3 General practitioner costs

The estimated costs related to primary care by general practitioners (GP) for people with epilepsy was $24.9 million in 2019-20. A large share of patients with epilepsy are treated exclusively by their general practitioner (GP) for seizures and epilepsy. According to D'Souza et al. (2009), 78% of patients were treated by their GP only in a study on patients with epilepsy in Tasmania. Fewer patients reported attending hospitals as outpatients or specialists (24.8%). Primary care therefore makes up an important part of patient treatment. The study also showed that the mean number of GP visits specifically for treatment of seizures and epilepsy was 3.3 over the previous 12 months of the survey period[68].

The annual number of GP visits for patients with epilepsy was estimated by applying the average number of visits of 3.3 to the prevalence of epilepsy. This results in 471,043 GP visits per year related to epilepsy treatment. See Appendix A for breakdown by jurisdiction. The average costs related to

[67] Ibid
[68] Lacey, C., Salzberg, M., Roberts, H., Trauer, T., & D'Souza, 2009, Psychiatric comorbidity and impact on health service utilization in a community sample of patients with epilepsy, Epilepsia, 50(8): 1991-1994

GP visits were based on Medicare Statistics from the Department of Health's Summary Statistics by Broad Type of Service.[69]

The average cost was derived using the total benefits provided for non-referred attendances, the number of services, the proportion of services that were bulk billed, and the average out of pocket costs. The average cost per visit was estimated for each jurisdiction. The overall national average cost per visit was estimated to be $51.1 in 2018-19 prices, and inflated to $52.9 with the health inflation rate. Table 3.3 below summarises the estimated costs related to annual GP consultations related to the treatment of epilepsy.

Table 3.3: Estimated GP costs related to epilepsy treatment, 2019-20

Component	Estimates
GP Visits (epilepsy related) (number)	471,043
Average cost ($), 2019-20 prices	52.9
Total cost ($ million), 2019-20 prices	**24.9**

Source: Department of Health Medicare Statistics (2018) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

3.4 Pathology and imaging costs

Neuroimaging such as magnetic resonance imaging (MRI), functional magnetic resonance imaging (fMRI) and computerised tomography (CT) as well as electroencephalogram (EEG) is central to the assessment and treatment management of patients with epilepsy. [70] Blood tests are also undertaken as part of the diagnosis of epilepsy, identifying the correct anti-epileptic drugs (AEDs) and monitoring the potential side-effects.[71]

The estimated costs related to imaging and pathology costs amounted to $10.4 million in 2019-20. On average, a GP orders 10.6 imaging tests and 45.5 pathology tests for every 100 patient visits in Australia[72]. The rate of diagnostic tests was applied to the estimated number of GP visits by patients with epilepsy calculated in 3.3. The average cost per imaging and pathology test ordered was sourced from the Department of Health's Medicare Statistics (Diagnostic Imaging and Pathology Statistics)[73]. The average costs were inflated to 2019-20 prices with the health inflation rate.

Table 3.4: Estimated pathology and imaging costs related to epilepsy (non-hospital), 2019-20

Component	Imaging tests	Pathology tests	Total
GP Visits (Epilepsy related) (number)	471,043	471,043	471,043
Number of tests ordered (number)	53,853	231,160	-
Average cost ($), 2019-20 prices	124	19	-
Total cost ($ million), 2019-20 prices	**6.2**	**4.2**	**10.4**

Source: Department of Health Medicare Statistics (2018) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

[69] Department of Health, Statistics under Medicare, available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/Statistics-1
[70] Salmenpera, J S., & Duncan, J, 2005, Imaging in epilepsy, Journal Neurology Neurosurgery and Psychiatry Vol 2005;76
[71] Epilepsy Foundation, available from: https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/seizure-and-epilepsy-medicines/blood-testing
[72] Britt H., Miller G.C., Henderson J., Bayram C., Harrison C., Valenti L., Pan Y., Charles J., Pollack A.J., Wong C., Gordon J. (2016). General practice activity in Australia 2015–16. General practice series no. 40. Sydney: Sydney University Press, 2016. Available from: purl.library.usyd.edu.au/sup/9781743325131
[73] Ibid

3.5 Medication costs

Anti-epileptic drugs (AEDs) are the main type of treatment for most people with epilepsy. Many epilepsy syndromes respond well to a specific drug or to a combination of drugs. Up to 60-70% of people diagnosed with epilepsy will gain seizure control through medication alone within a year.[74] AEDs aims to stop seizures from happening but do not stop a seizure once it has started and cannot cure epilepsy. The total annual medication costs are estimated to be $262.1 million in 2019-20, as summarised in Table 3.5.

According to the Australian Epilepsy Longitudinal Survey (Wave 3), approximately 95.5% of people surveyed took medication to control epilepsy, which results in 136,297 medicine reliant individuals in 2019-20.[75] The average annual patient and government contributions to medication was estimated to be $786 and $1,214 per person (2019-20 prices).[76] [77] The patient contribution is the average weighted cost of epilepsy medication from the Longitudinal Survey (Wave 3) responses, while the government contribution was based on government contribution share across several AED medications on the Pharmaceutical Benefit Scheme[78]. See Appendix A for breakdown by jurisdiction.

Table 3.5: Estimated pharmaceutical costs related to epilepsy, 2019-20

Component	Estimates
Medicine reliant patients (number)	136,297
Average patient contribution ($), 2019-20 prices	786
Average government contribution ($) 2019-20 prices	1,214
Total cost ($ million), 2019-20 prices	**262.1**

Source: Epilepsy Foundation Longitudinal Survey of People with Epilepsy Wave 3 (2014) and Pharmaceutical Benefits Scheme Statistics (2019). A CPI rate of 2.1% annually is applied to inflate costs to 2019-20 prices. Note: These numbers may vary slightly due to rounding.

3.6 Research costs

In order to analyse the amount of expenditure on epilepsy or epileptic related research, this study utilised the National Health and Medical Research Council (NHMRC) grants database. The database contains an extensive list of the research awarded grant funding between 2000 and 2016 as well as keywords and titles of research[79]. To estimate the amount of expenditure, the total amount of grants for research that explicitly includes epilepsy in the title of the grant funding proposal was used. Furthermore, the data was adjusted to account for duplicated grant ID's to avoid any instance of double counting. The costs were inflated to 2019-20 prices with the consumer price index. The total annual research funding is estimated to be $28.8 million in 2019-20 prices.

3.7 Summary - Health system costs

The total annual estimated health care expenditure on epilepsy was $557.1 million in 2019-20. Lifetime costs for healthcare were estimated to be $897.6 million. To estimate the lifetime costs of health system expenditure, health system expenditure was divided by prevalence to derive a unit cost. The unit costs for each cost component of health system expenditure were then projected out, for the number of incident cases, assuming a life expectancy of 82 years. Lifetime costs assumed that only the proportion of individuals with severe epilepsy (i.e. resistant to antiepileptic drugs) need

[74] Epilepsy Australia 2018, Epilepsy Treatment. Available at: http://www.epilepsyaustralia.net/epilepsy-treatment/, accessed March 2019.
[75] Epilepsy Foundation, 2014, Australian Epilepsy Longitudinal Study, Wave 3: The Social Impact of Epilepsy
[76] Ibid
[77] Department of Health, 2019, Pharmaceutical Benefits Scheme Statistics, available from: https://www.pbs.gov.au/info/browse/statistics
[78] Department of Health, 2019, Pharmaceutical Benefits Scheme Statistics, available from: https://www.pbs.gov.au/info/browse/statistics
Note: The AED contribution split was based on contributions for PBS listed medications: carbamazepine, lamotrigine, vigabatrin, gabapentin, clonazepam and ethosuximide.
[79] National Health and Medical Research Council (NHMRC), 2018, All Grants 2000-2016. Research Funding Statistics and Data. Available from: https://www.nhmrc.gov.au/grants-funding/research-funding- statistics-and-data.

acute and sub-acute hospital services for the remainder of their lives. All lifetime costs were discounted by 3% per annum, to derive the net present value of costs in 2019-20 (Table 3.6).

Table 3.6: Estimated health care expenditure on epilepsy by component , 2019-20

Cost component	Annual costs ($ m)	Lifetime costs ($ m)
Hospital (sub-acute)	29.5	66.3
Hospital (acute)	169.8	114.3
Outpatient cost	31.5	21.2
Medication	262.1	587.9
GP consultation	24.9	55.9
Diagnostics	10.4	23.3
Research	28.8	28.8
Total	**557.1**	**897.6**

Source: Deloitte Access Economics estimates

The burden of annual and lifetime health costs have been estimated to largely fall on individuals and state governments, as illustrated in Table 3.7. For health system expenditure, the burden of costs by cost bearer has been derived from a bottom-up approach. Specifically, hospital costs were assumed to be borne by state and territory governments, and the majority of GP-related, diagnostics and research costs were assumed to be borne by the Commonwealth government. Individuals bear around 41% of medication costs, with the Commonwealth government bearing the remainder. In terms of GP-related costs, individuals bear approximately one fifth of the total and the remained is borne by the Commonwealth government.[80] This is illustrated in Table 3.7 and Figure 3.1.

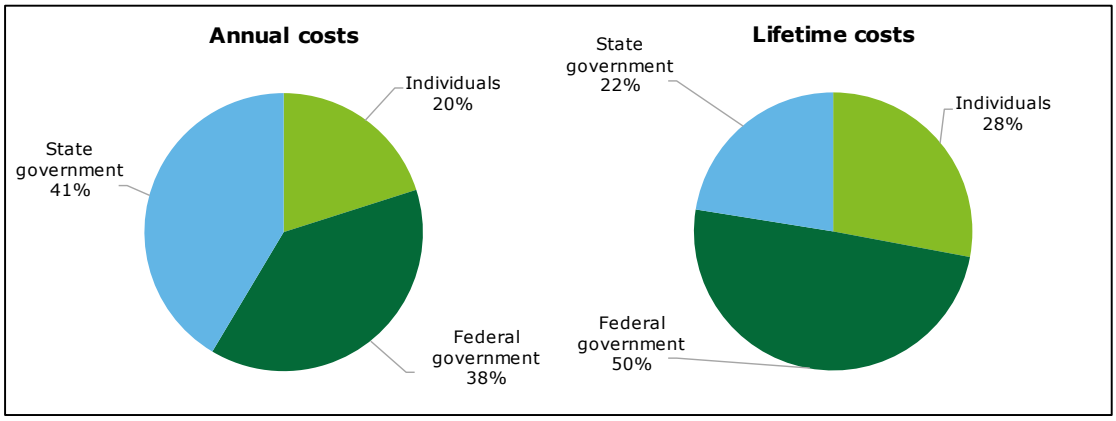
Table 3.7: Proportion of healthcare costs of epilepsy by cost bearer, 2019-20

Cost bearer	Annual costs ($m)	% of total costs	Lifetime costs ($m)	% of total costs
Individuals	111.9	20%	250.9	28%
Federal government	214.4	38%	445.0	50%
State government	230.9	41%	201.7	22%
Total	**557.1**	**100%**	**897.6**	**100%**

Source: Deloitte Access Economics estimates

[80] The proportion of GP related costs borne by individuals was derived based on the mean value of the out-of-pocket rate of non-referred GP attendances from each state and territory.

Figure 3.1: Breakdown of annual and lifetime healthcare costs of epilepsy, by cost bearer (2019-20)



Source: Deloitte Access Economics estimates

4 Other financial costs

Epilepsy imposes a substantial burden on individuals, carers and society as a whole. A significant portion of this can be attributed to factors outside of the healthcare system. For the most part, these are costs related to the loss of productivity attributable to epilepsy-related morbidity and mortality. However, it also encompasses the cost to informal carers and deadweight losses associated with the loss of income and increased government welfare burden.

Understanding this cost component is of critical importance to knowing the complete burden of disease profile of epilepsy. That is, without understanding the costs beyond those imposed directly on the healthcare system, it is not possible to accurately distribute resources toward the treatment and prevention of the condition.

4.1 Productivity

Productivity losses are common in people living with epilepsy due to their overall worse health outcomes relative to the general population.[81] There are a number of channels through which individual health can affect labour supply and productivity. This is primarily due to reduced workforce participation, but may also be a result of increased absenteeism from work (for example, to attend medical appointments), having to reduce participation in the workforce or exit the labour force entirely, and reduced lifetime earnings potential due to premature death.

4.1.1 Absenteeism

Absenteeism represents the cost of being unwell more often than average, and taking time off work, while remaining in the workforce. For instance, those diagnosed with epilepsy may take time off work in the short-term due to medical appointments or from associated health conditions such as sleep disorders and migraine. Short-term costs of absenteeism are assumed to borne by employees, in the form of lost earnings, and by employer, in terms of replacement costs. The cost to the employee is assumed to be earnings lost from each day absent at work. This depends on:

- The proportion of workers who take time off work for sick leave
- The average number of days absent from work
- The average earnings per employee

According to the results of the Australian Epilepsy Longitudinal Survey (Wave 3), over a quarter (29%) of respondents indicated that they were absent from work due to epilepsy during the last 12 months.[82] On average, each person who was absent from work reported an average of 33 days of absence. The costs of absenteeism borne by the employee is estimated to be $145.4 million in 2019-20, as shown in Table 4.2.[83] When extended over the lifetime of each new case of epilepsy in 2019-20, absenteeism is estimated to cost employees $259.2 million.

Additionally, the costs of absenteeism borne by the employer includes:

- Overtime premium for a replacement worker due to absenteeism
- Replacement costs, i.e. the costs of training the new worker into the role of the absent individual

That is, the cost of an employee taking time off includes the additional costs of existing workers to work overtime to maintain work output. The overtime premium is assumed to be an additional 40% of current average weekly earnings.[84] Replacement costs were assumed to be the lost productivity stemming from the hours a manager in a workplace has to take off to train a replacement employee.

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[81] Gillam, F. (2002). Optimizing health outcomes in active epilepsy. *Neurology*, 58(8):9-20.
[82] Epilepsy Foundation (2014), Australian Epilepsy Longitudinal Study Wave 3: The Social Impact of Epilepsy. Note that 75 individuals out of 263 respondents noted that they were absent from work due to epilepsy in the previous 12 months.
[83] The cost of absenteeism was estimated by multiplying prevalence estimates with average weekly earnings by age and gender, the proportion of workers who take sick leave and the average number of days in a year that an individual with epilepsy would be absent from work.
[84] Safe Work Australia (2015) The Cost of Work-related Injury and Illness for Australian Employers, Workers and the Community 2012–13, Canberra, ISBN 1 920763 58 9.

The number of hours per day required for the manager to take off was 2.5, based on the costs to Britain of workplace injuries and work-related ill health in 2006-07.[85] The cost of lost productivity was assumed to be equivalent to the hourly wage of the manager, which was imputed by dividing average weekly earnings for a manager, divided by an assumed 37.5 hour work week.[86] Based on these assumptions, the cost to employers of absenteeism due to epilepsy in Australia in 2019-20 is estimated to be $953.0 million, as shown in Table 4.2. When this absenteeism is projected over the lifetime of each person diagnosed with epilepsy for the first time in 2019-20, it is estimated to cost $1.7 billion.

Productivity in terms of presenteeism has not been included in productivity losses, as productivity losses from epilepsy are assumed to stem from absenteeism (4.1.1) and longer-term reduction in workforce participation (4.1.2). That is, an individual diagnosed with epilepsy is assumed to take time off work due to adverse health conditions, rather than come to work and not be fully productive. Individuals diagnosed with epilepsy were also assumed to have reduced employment prospects in the longer-term. The costs of associated with lower workforce participation in the longer-term has been factored into productivity costs, as discussed in 4.1.2.

Estimates of presenteeism due to seizure disorders have been reported by Allen et al (2018), based on a retrospective prevalence study on a group of employees in the United States.[87] The study reported that the estimated average productivity loss per person diagnosed with seizure disorders was two minutes per day. Assuming that the number of work days per year is 261, the number of hours lost per year attributable to presenteeism is 8.7 hours or just over a day's work. Given that the productivity losses associated with epilepsy are likely to be related to absenteeism and reduced employment in the longer-term, the costs of presenteeism were not included.

4.1.2 Reduced workforce participation

In addition to the temporary costs of absenteeism, there is a longer-term, human capital cost. This longer term cost stems from the reduced workforce participation of individuals diagnosed with epilepsy.

According to the survey results from the Australian Epilepsy Longitudinal Study (Wave 3), 49% of individuals aged between 18 to 60 years of age who indicated that they were employed were in full time employment, with the remaining 51% in either part time or casual work.[88] This suggests difficulties in being employed full-time. Overall in Australia, around 76% of employees were in full time employment while 24% were in part-time work, in February 2019.[89] Furthermore, the Australian Epilepsy Longitudinal Study (Wave 3) suggested that around one-third of respondents who were unemployed were unable to work due to epilepsy or another disability.[90] This further suggests that there may be significant barriers to participation in the workforce.

In a review of Australian health and social welfare policies relating to epilepsy, undertaken by the Epilepsy Foundation, it was noted that attitudes of workplaces towards epilepsy played a role in the employability of persons diagnosed with epilepsy.[91] This is despite the fact that seizure types, severity and side effects of medications play a role in employability as well. Further, the report noted that unemployment of people with epilepsy in Australia is likely to be very high, with possibly only 30% of individuals with epilepsy employed full time, and 17% part time.

In a United Kingdom study examining labour market participation following onset of early epilepsy, it was reported that the employment rate of individuals with epilepsy was almost 20 percentage

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[85] Health and Safety Executive (2011), The costs to Britain of workplace injuries and work-related ill health in 2006/07: Workplace fatalities and self-reports, Prepared by Risk Solutions, Warrington, England.
[86] Australian Bureau of Statistics (2018), Employee Earnings and Hours – 6306.0, Australia, May 2018.
[87] Allen, D., Hines, E.W., Pazdernik, V., Konecny, L.T. and Breitenbach, E., 2018. Four-year review of presenteeism data among employees of a large United States health care system: a retrospective prevalence study. Human resources for health, 16(1), p.59.
[88] Of the 324 survey respondents, 128 people aged 18 to 60 years old indicated they were employed. Out of this cohort, 63 mentioned that they were employed full time, 41 were employed part time and 24 were employed on a casual basis.
[89] Australian Bureau of Statistics, 6202.0 - Labour Force, Australia, Feb 2019, accessed at http://www.abs.gov.au/ausstats/abs@.nsf/mf/6202.0
[90] Epilepsy Foundation (2014), Australian Epilepsy Longitudinal Study Wave 3: The Social Impact of Epilepsy.
[91] Epilepsy Foundation of Victoria (2008), Epilepsy in Australian policy, Available at: https://www.epilepsyfoundation.org.au/wp-content/uploads/2016/12/Walker-Policy-and-epilepsy-in-Australia-Jan09-Final.pdf, accessed March 2019.

points lower than the general population for men, and 13 percentage points lower for women. This was after a two-year study follow-up period. Table 4.1 reports the employment rates for working age men and women diagnosed with epilepsy, against employment rates of the general population. The estimates are based on a UK cohort. For the purpose of this study, reduced workforce participation costs were based on these results.

Table 4.1: Employment rates (UK) in the general population and for individuals with epilepsy

Gender-age cohort	Employment rate (%), General population	Employment rate (%), individuals with epilepsy	Differential (percentage points)
Men, 16-60 employed	80.6	60.8	19.8
Women, 16-55 employed	81.1	68.0	13.1

Source: Holland et al. (2009)

Assuming that employees diagnosed with epilepsy would have earned the same as their colleagues, the total annual cost of reduced labour force participation is $912.2 million in 2019-20. When extended over the lifetime of all new cases of epilepsy diagnosed in 2019-20, the cost of reduced labour force participation is estimated to be $1.6 billion. This assumes that individuals enter employment from 15 years of age, and retire at 65 years. These costs are summarised in Table 4.2.

4.1.3 Productivity loss from premature mortality

The premature death of those with epilepsy results in a future stream of productivity losses that can be approximated through lost potential earnings up to retirement age, assumed to be 65 years. There are an estimated 342 deaths attributable to epilepsy in 2019, a figure derived from the 322 reported by the AIHW in 2015 (refer to section 2.3).

The productivity lost due to premature death was calculated by multiplying the number of deaths that resulted from epilepsy in the working age population, by the age-specific employment rate and remaining expected lifetime earnings at the time of death. Calculations assumed that people enter the workforce at the age of 15 and retire at the age of 65. The remaining years of employment were calculated by starting at the midpoint of each working age cohort at the time of death. Finally, all lifetime costs were discounted by 3% per annum to derive the net present value of future potential earnings that were not realised due to premature mortality. The total annual cost associated with premature mortality is estimated to be $316 million in 2019-20, climbing to $502.1 million for lifetime costs.

Table 4.2 summarises each component of productivity losses, both in 2019-20 annual terms and extended over the lifetime of each new case of epilepsy in 2019-20.

Table 4.2: Productivity cost breakdown ($ million), 2019-20

Period	Absenteeism – employee	Absenteeism - employer	Reduced employment	Premature mortality	Total
Annual	145.4	953.0	912.2	316.0	**2,326.6**
Lifetime	259.2	1,699.4	1,625.9	502.1	**4,086.6**

Source: Deloitte Access Economics estimates

4.2 Informal care costs

The costs of epilepsy may also fall on individuals who provide informal care for people living with epilepsy, such as partners, parents, siblings and other relatives. These individuals provide care and assistance to people living with epilepsy on an unpaid basis. While the care they provide is unpaid in a financial sense, it is not free in an economic sense, as the time they spend caring cannot be directed to other productive activities such as paid work, unpaid work or leisure.

The channels through which this may occur are largely similar to those listed above. That is, when an individual experiences a seizure event, it may lead to absenteeism from informal carers who have

to tend to their needs. In some severe cases, these individuals may make the decision to exit the labour force to provide full-time care to the individual, hence reducing their overall employment.

Estimating a dollar value of epilepsy-related informal care involves viewing the time spent by carers as an opportunity cost. That is, the method measures the formal sector productivity losses associated with the time spent caring, as this time cannot be spent in the paid workforce. As such, it was necessary to estimate the proportion of people living with epilepsy who receive support from an informal carer.

Informal care provision hours were estimated by averaging estimates found within the literature. From these studies, an average of 28.3 hours per week was taken to be the standard informal care requirement for a person living with epilepsy who requires informal care.[92,93,94,95,96] It is also necessary to isolate only the additional hours of care that are provided to Australians with epilepsy. The Survey of Disability, Ageing and Carers (SDAC) can be used for this purpose. Within this, it was found that an average care requirement of people without disabilities caused by epilepsy and no known health conditions is 15.9 hours per week.

The incremental care provision of 12.4 hours per week was applied to the percentage of people with epilepsy who require informal care. In the context of epilepsy, it was assumed that only those with drug-resistant epilepsy (DRE) would require ongoing informal care. This has been estimated as being 30-40% of all people with epilepsy. However, it is possible that this may overestimate the true extent of informal care requirements, as there are significant differences in severity of condition among this group. As such, 30% of people living with epilepsy were assumed to require some level of informal care to minimise the possibility of overestimating the actual cost.

For these people receiving informal care for epilepsy, it was estimated that an additional 654 hours of care are required annually. This is equivalent to an additional 27.6 million hours of care annually across the 30% of people living with DRE. To estimate the value of this time, it was assumed that informal carers have approximately the same age and gender distribution as the person with epilepsy. This assumption informs the valuation of the carer's opportunity cost of time, which is based on weighted average weekly earnings (AWE)[97] and the chance of being employed.[98] From this, the average opportunity cost of a carer's time was estimated to be $15.40 per hour.

Overall, the total cost of informal care for Australians with epilepsy was estimated to be $438.2 million in 2019-20. Lifetime costs of informal care were derived by projecting out the number of years that the of individuals required care.

The carer profile for epilepsy was based on a general survey of carers for people with mental illness. Based on the survey by Carers Victoria (2013):[99]

- 16% of carers noted that they had to care for people for up to 5 years
- 38% of carers noted that they had to care for people for 5 to 10 years
- The remaining 46% noted that they had to care for people for more than 10 years.

As there was no data for individuals diagnosed with epilepsy on duration of care, for the purposes of this report, it was assumed that 16% of individuals who are just diagnosed with epilepsy required

[92] Van Andel, J., Zijlmans, K., Fischer, K., & Leijten, F. S. S. (2009). Quality of life of caregivers of patients with intractable epilepsy. *Epilepsia*, 50(5):1294-1296.
[93] Karakis, I., Cole, A. J., Montouris, G. D., Luciano, M. S., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. *Epilepsy Research and Treatment*, 2014, 808421.
[94] Helmers, S., Gupta, S., Huang, S., Berk, A., & Knoth, R. (2015). Caregiver burden: An under-recognised aspect of epilepsy care. *Kantar Health*.
[95] Mitchell, L. A., Hirdes, J., Poss, J. W., Slegers-Boyd, C., Caldarelli, H., & Martin, L. (2015). Informal caregivers of clients with neurological conditions: Profiles, patterns and risk factors for distress from a home care prevalence study. *BMC Health Services Research*, 15:350.
[96] Campbell, J. D., Whittington, M. D., Kim, C. H., VanderVeen, G. R., Knupp, K. G., Gammaitoni, A. (2018). Assessing the impact of caring for a child with Dravet syndrome: Results of a caregiver survey. *Epilepsy & Behaviour*, 80:152-156.
[97] ABS (2019), Average weekly earnings, Australia, Nov 2018, cat. no. 6302.0.
[98] ABS (2018a). Labour force, Australia, Detailed, Quarterly, Aug 2018, cat. no. 6291.0.55.003.
[99] Carers Victoria (2013) Invisible care: Access to Carer Payment and Carer Allowance by Victorian carers of a person with mental illness. Melbourne, August 2013.

care for up to 5 years, 38% required care for 8 years and the remaining of newly diagnosed epilepsy cases required lifetime care.

Unit costs of care were projected out until the expected age of death at 82 years. All lifetime costs were discounted by 3% to derive the net present value of costs for 2019-20. Lifetime costs of informal care were estimated to be $598.8 million in 2019-20. Table 4.3 summarises the annual and lifetime costs of informal care.

Table 4.3: Informal care costs ($ million), 2019-20

Period	Informal care
Annual	438.2
Lifetime	598.8

Source: Deloitte Access Economics estimates

4.3 Equipment costs

Epilepsy can significantly impact the capacity of a person to conduct activities of daily life. The unpredictable nature of seizure onset can disrupt almost any day-to-day activity. As such, some individuals require equipment and devices to assist them in safely conducting daily activities, and to alert carers in the event of a seizure. These devices are those used outside the health system.

Using data from the Longitudinal Survey of People with Epilepsy (Wave 4), an average annual cost of the most common epilepsy-specific devices was estimated.[100] This survey showed that emergency ID bracelets (n=89), seizure alarms (n=43), seizure monitors (n=40) and anti-suffocation pillows (n=39) are the most commonly required devices for people living with epilepsy. It is assumed that the equipment and devices need to be replaced every three years. The total annual cost of these devices is presented in Table 4.4.

Table 4.4: Estimated equipment and devices costs, 2019-20

Type of equipment	Used by (%)	Unit cost ($ total)	Unit cost ($ annual)	Total cost ($m annual)
Emergency ID bracelet	23.2	8	26.7	0.9
Seizure alarm	11.2	397	132.3	2.1
Seizure monitor	10.4	949	316.3	4.7
Anti-suffocation pillow	10.2	189	63.0	0.9
Total	**-**	**-**	**-**	**8.6**

Source: Epilepsy Foundation, Epilepsy Longitudinal Survey, Wave 4 (2017)

From this, a total annual cost per person was derived by dividing by the total number of prevalent cases of epilepsy in 2019-20. In total, this equated to an average annual cost of $60.51 for each of the 142,740 people living with active epilepsy in 2019-20. The total annual equipment cost was estimated to be $8.6 million in 2019-20.

For lifetime costs, the unit cost of equipment was multiplied by the estimated number of incidence cases in 2019-20, and projected out to the lifetime of the individual, where age of death is 82 years old. Further it was assumed that individuals had to incur equipment costs every three years due to depreciation and the need to replace old equipment. All lifetime costs were discounted by 3%, to derive the net present value of costs for 2019-20. Table 4.5 summarises the annual and lifetime costs of equipment for patients diagnosed with epilepsy.

[100] Epilepsy Foundation, 2017, Summary of the Australian Epilepsy Longitudinal Survey – Wave 4, Accessed from: http://www.epilepsyaustralia.net/uploads/74689/ufiles/Wave_4_Report_summary.pdf

Table 4.5: Equipment cost breakdown ($ million), 2019-20

Period	Equipment costs
Annual	8.6
Lifetime	6.7

Source: Deloitte Access Economics estimates

4.4 Transport costs

In many cases, a person living with epilepsy is unable to safely drive a motor vehicle. In particular, people whose have conditions in which seizures cannot be controlled by medication are generally unable to obtain a driver's license. In these severe cases, the individual also may not be able to safely use public transport due to the possibility of having a seizure in an unsafe environment.

Where other individuals are able to transport themselves to medical appointments, either through use of a motor vehicle or public transport, people living with DRE often have to use taxis. This can place an additional financial burden on people living with DRE. To estimate the incremental component of this burden imposed on people living with DRE, we estimate the difference between an average individual's expenditure and that expended by a person living with DRE.

Specifically, this is calculated as the average cost per kilometre travelling in a taxi minus the average cost per kilometre driving, multiplied by the average number of neurologist and GP trips needed by a person living with epilepsy, the average distance per trip, and the number of people living with DRE. This is presented in Table 4.6 below.

Table 4.6: Estimated transport costs, 2019-20

Component	Value
Average cost per km - taxi travel ($)	2.79
Average cost per km - driving ($)	0.48
Average number of trips annually - neurologist & GP	5
Average distance per trip (km)	20
Number of people living with DRE	42,822
Total cost ($m)	**9.9**

Source: Australian Taxi Industry Association (2014), Transport for NSW (2018), Deloitte Access Economics estimates

As can be seen in Table 4.6, the total annual cost for transport is estimated to be $9.9 million in 2019-20. This represents a cost of $231 per person living with DRE in 2019-20. For lifetime costs, the per person cost of transport was multiplied by the estimated number of incident cases in 2019-20, and projected out to the lifetime of the individual, where the expected age of death is 82 years old. All lifetime costs were discounted by 3%, to derive the net present value of costs for 2019-20, which is $20.8 million. Table 4.7 presents the total estimated cost of transport, both in 2019-20 annual terms and the lifetime cost of all new cases of epilepsy occurring in 2019-20.

Table 4.7: Transport cost breakdown ($ million), 2019-20

Period	Transport costs
Annual	9.9
Lifetime	20.8

Source: Deloitte Access Economics estimates

4.5 Deadweight loss

A deadweight loss is defined as a loss of economic efficiency that occurs when equilibrium is not achieved in a market. In the case of epilepsy, this arises due to the government's need to collect additional tax revenue to fund costs that would otherwise not have been incurred.

There are frictions associated with the collection of additional tax revenue. Specifically, increases in tax reduce the efficiency with which resources are allocated within an economy. This may be through higher income taxes, which increases the price of work relative to leisure and therefore creates a disincentive to work. Additionally, higher sales taxes increases the cost of goods and services and results in a loss of sales to businesses. These mechanisms result in a reduction in consumer and producer surplus, respectively, which is known as the deadweight loss, or excess burden, of tax.

There are a number of channels through which deadweight losses may arise. In the case of epilepsy, the most relevant of these are welfare payments provided to people living with epilepsy, welfare payments to those who care for someone living with epilepsy, and through lower taxation as a result of reduced employment. Welfare payments attributed to epilepsy considered for this study include the Disability Support Pension (DSP), the National Disability Insurance Scheme (NDIS) as well as Carer Allowance and Payments.

4.5.1 Welfare payments for individuals with epilepsy (DSP)

The most commonly received work-related welfare benefit is the Disability Support Pension (DSP). Eligibility for the DSP is for individuals aged 16 years and older, who have a permanent medical condition that prevents them from working. Other less common support payments include the Newstart Allowance (NSA) and the Sickness Allowance (SKA), however these were not included in the modelling due to a negligible sample size.

Data on DSP welfare payments were obtained from the Department of Social Services (DSS) through a special data request. According to data from the DSS, there were 19,656 recipients of the DSP in December 2018 whose primary medical condition was epilepsy. The average payment to these individuals was derived by dividing total payments made through the DSP by the total number of recipients. Using this approach, it was estimated that the average annual value of support to recipients living with epilepsy was $22,879 in 2019-20. In total, it was estimated that $451.8 million was paid to people living with epilepsy through the DSP in 2019-20.

However, some of these recipients would be expected to receive welfare payments irrespective of their condition, meaning that the total must be adjusted to account for this. The general 'reliance' on income support in Australia has been estimated at 13%.[101] As such, the total DSP payments to people living with epilepsy was adjusted down to $392.2 million, which represents only the additional payments made as a result of epilepsy. The total deadweight losses from this expenditure is discussed in 4.5.4.

4.5.2 Welfare payments for individuals with epilepsy (NDIS)

The National Disability Insurance Scheme (NDIS) provides support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disability who meet eligibility requirements. It funds a range of supports and services that are considered 'reasonable and necessary', including: education, employment, social participation, independence, living arrangements and health and wellbeing. For those who qualify for NDIS supports, they are then able to create a plan with the support of Local Area Coordinators (LACs) who assist in developing budgets and managing supports.

Epilepsy is a chronic condition, particularly for people with drug-resistant epilepsy. The condition on its own, or as a secondary condition to other disabilities, meets the requirements of the National Disability Insurance Scheme Act 2013, Section 24, which attributes disabilities to one more or intellectual, cognitive, neurological, sensory or physical impairments.

However, the list of conditions provided in the Act that are likely to meet the disability requirements in Section 24 does not list epilepsy under conditions resulting from neurological impairments or disorders of the nervous system. Anecdotal evidence suggests that people living with epilepsy as a secondary condition to another listed primary condition are therefore more likely to access support through the NDIS. In contrast, people whose primary condition is epilepsy may face access issues.

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[101] Tseng, Y. P., & Wilkins, R. (2003). Reliance on income support in Australia: Prevalence and persistence. *Economic Record*, 79(245): 196-217.

Data provided by the National Disability Insurance Agency, through a special data request, show that 725 participants with current NDIS plans had epilepsy as a primary disability, while 11,693 had epilepsy as a secondary disability (as at March 31, 2019). The average annual committed support for these recipients was $72,532 when epilepsy was the primary condition, and $133,057 when epilepsy was the secondary condition. For the purposes of this report, we take a conservative approach using the $72,532, to isolate the portion of support plans directly attributable to epilepsy-related issues.

The incremental cost related to epilepsy was estimated to be $900.7 million, using only the value of support for participants with epilepsy as primary condition. Similar to the methodology for the DSP in 4.5.1 above, the total NDIS payments to people living with epilepsy was adjusted down to $781.8 million, to account for the general 'reliance' factor. The total deadweight loss from this expenditure is discussed in 4.5.4.

It should be noted that reported figures may underestimate the true extent of welfare payments made to people living with epilepsy, both through the DSP and the NDIS. Anecdotally, this is due to epilepsy's classification and the episodic nature of the condition, meaning it is often difficult for individuals to meet eligibility requirements. In some cases, people living with epilepsy opt to apply for disability support citing other conditions, such as developmental delays or other mental health conditions, for example. For these reasons, the estimated costs associated with welfare payments to people living with epilepsy may be conservative.

4.5.3 Welfare payments for carers

Epilepsy also requires many individuals to provide ongoing care to people living with the condition, particularly for those who have drug-resistant epilepsy (DRE). These individuals often have to reduce their labour force participation or exit the workforce entirely to meet their carer requirements. As such, epilepsy is also associated with welfare payments to these carers who cannot support themselves. The most common of these payments is the Carers Payment and the Carers Allowance.

These payments are available to any person who provides constant care in the home to an individual with a physical, intellectual or psychiatric disability. As per the Department of Social Services' List of Recognised Disabilities,[102] epilepsy cases are only considered eligible when seizures are uncontrolled while on medication. To derive the average payment per person caring for someone living with epilepsy, the total annual Carer Payment and Carer Allowance was estimated. The average weekly Carer Payment and Carer Allowance were taken to be $281.9 and $64.9, respectively, as per the Department of Human Services.[103] According to data from the DSS, as of December 2018 there were 10,246 and 22,476 individuals caring for a person living with epilepsy receiving the Carer Payment and Carer Allowance, respectively. Applying the average payment rates to these figures gives an annual payment of approximately $226.1 million, or $6,909 per carer for people with epilepsy. The deadweight losses associated with these payments to carers is discussed in 4.5.4.

4.5.4 Deadweight losses from welfare payments

In order to determine to deadweight losses resulting from welfare payments, an efficiency loss rate was applied to the welfare payments incurred. The rate of efficiency loss reflects the average deadweight losses associated with raising income and indirect taxes, and is explained in further detail in 4.5.5. An efficiency loss rate of 29% is applied to Commonwealth grant expenditure. Both NDIS and DSP payments fall under the Commonwealth.

As shown in Table 4.8, an estimated $392.2 million and $781.8 million was spent under DSP and NDIS, respectively, to people living with epilepsy in 2019-20. When the rate of efficiency loss of 29% from generating extra taxation is applied, the total annual deadweight loss is estimated to be $113.8 million and $226.8 million for DSP and NDIS, respectively. Adding the estimated $65.6 million in deadweight losses associated with the $226.1 million in welfare payments to carers in 2019-20, the total annual deadweight losses from welfare payments is estimated to be $406.2 million in 2019-20.

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[102] Department of Social Services 2018, Disability and carers: Guide to the list of recognised disabilities. Available at: https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carer-allowance/guide-to-the-list-of-recognised-disabilities, accessed April 2019.
[103] Department of Human Services 2019, Carer allowance: Payment rates. Available at: https://www.humanservices.gov.au/individuals/services/centrelink/carer-allowance/eligibility/payment-rates, accessed March 2019.

Table 4.8: Estimated annual deadweight loss from welfare payments, 2019-20

	People living with epilepsy		Carers	Total
	DSP	NDIS		
Cost component ($m)	392.2	781.8	226.1	1,400.1
Rate of efficiency loss (%)	29.0	29.0	29.0	29.0
Deadweight loss ($m)	**113.8**	**226.8**	**65.6**	**406.2**

Source: Deloitte Access Economics estimates

Table 4.9 presents the estimated deadweight losses from welfare payments made over the lifetime of newly diagnosed epilepsy cases in 2019-20. It is estimated that people living with epilepsy incur $1,993.6 million worth of support payments ($776.7 million from DSP and $1,216.9 million for NDIS) and their carers a further $404.2 million. When the rate of efficiency loss of 29% from generating the extra taxation required is applied, the deadweight losses associated with people living with the condition are estimated to be $225.3 million for the DSP and $353.0 million for the NDIS. The deadweight losses associated with support payments made to their carers is $117.3 million. This amounts to a total lifetime deadweight loss of $695.6 million from welfare payments, at a rate of efficiency loss of 29%.

Table 4.9: Estimated lifetime deadweight losses from welfare payments, new cases in 2019-20

	People living with epilepsy		Carers	Total
	DSP	NDIS		
Cost component ($m)	776.7	1,216.9	404.2	2,397.9
Rate of efficiency loss (%)	29.0	29.0	29.0	29.0
Deadweight loss ($m)	**225.3**	**353.0**	**117.3**	**695.6**

Source: Deloitte Access Economics estimates

4.5.5 Deadweight loss of taxation payments and administration

Reduced earnings from lower employment participation and lower output result in reduced taxation revenue collected by the Government. Along with forgone income taxation, there is an associated fall in indirect (consumption) taxes, as those with lower incomes spend less on the consumption of goods and services. Lost taxation revenue was estimated by applying an average personal income tax rate and average indirect taxation rate to lost earnings.

The average rates of taxation were derived by dividing net income tax and net indirect tax by the taxable income. This method was also used to derive the average company tax rate, which was then applied to lost company earnings (through reduced output). Again, net tax for companies was divided by the total taxable income for companies. The respective tax rates used in the calculation of deadweight losses were:[104]

- 23.4% average personal income tax rate, and 12.6% average indirect tax rate.
- 22.9% average company tax rate.

To estimate the deadweight loss due to lost taxation revenue (given an assumption of no change in spending), taxes were assumed to be maintained by taxing either individuals or companies more as necessary (to replace the lost tax from either stream). Each tax in the economy imposes various burden on the efficiency of society.

[104] Australian Taxation Office 2018, Taxation Statistics 2015-16, available at: https://www.ato.gov.au/About-ATO/Research-and-statistics/In-detail/Taxation-statistics/Taxation-statistics---previous-editions/Taxation-statistics-2015-16/, accessed March 2019.

Analysis by KPMG (2010) and Cao et al (2015) report the marginal burden of various government taxes (both State and Commonwealth).[105] [106] Briefly:

- Income tax has been estimated to impose a burden of $0.25 for every $1 raised
- Company tax has been estimated to impose a burden of $0.50 for every $1 raised
- Goods and services tax has been estimated to impose a burden of $0.19 for every $1 raised
- State taxes were estimated to impose a burden of $0.45 for every $1 raised based on the respective shares of revenue raised through major state taxes including gambling, insurance, motor vehicle taxes, payroll tax and stamp duties.[107] [108]

Efficiency loss rates reflects the average deadweight losses associated with raising income and indirect taxes to provide government services. It is important to consider Commonwealth and state and territory taxes as jurisdictions pay for a proportion of health and human services. Thus, the relevant burden imposed by taxation is allocated to both income taxes, and the weighted Commonwealth and state and territory taxes. Weighted by the revenue raised:

- Reduced income for individuals results in a 23.7% efficiency loss
- Reduced income for employers results in a 50.8% efficiency loss
- Commonwealth welfare payments (section 4.5.4) and health expenditure result in a 29.0% efficiency loss
- State health expenditure results in a 37.9% efficiency loss.

Table 4.10 to Table 4.13 show the estimated deadweight losses associated with both health system expenditure and lost taxation, the applied rates of efficiency loss of raising taxation, and resultant deadweight losses. All rates of efficiency loss include a 0.8% administrative loss which covers expenses of administering taxation.[109]

The total annual deadweight losses associated with health system expenditure amounts to $149.6 million. Based on the 2017-18 Federal Budget, approximately 69% of state and territory health expenditure is paid for by state and territory taxes, while the remaining 31% is paid for by transfers from the Commonwealth. Therefore, it is estimated that $62.2 million of the loss is attributable to the Federal government expenditure while the remaining $87.4 million is attributable to the State government. The overall rate of efficiency loss is estimated to be 33.6%.

Table 4.10: Estimated annual deadweight losses from health system expenditure, 2019-20

	Federal gov.	State gov.	Total
Cost component ($m)	214.4	230.9	445.3
Rate of efficiency loss (%)	29.0	37.9	33.6
Deadweight loss ($m)	**62.2**	**87.4**	**149.6**

Source: Deloitte Access Economics estimates

The lifetime deadweight losses associated with health expenditure incurred by all new cases of epilepsy in 2019-20 totals $205.5 million. This is comprised of $129.1 million attributable to the Federal government and $76.4 million to the State government, with an overall efficiency loss of 31.8%.

[105] KPMG Econtech (2010). CGE analysis of the current Australian tax system. Report for the Australian Government the Treasury, March, Canberra.
[106] Cao L, Hosking A, Kouparitsas M, Mullaly D, Rimmer X, Shi Q, Stark W, Wende S. (2015). Understanding the economy-wide efficiency and incidence of major Australian taxes', The Australian Government the Treasury, Canberra.
[107] KPMG Econtech (2010). CGE analysis of the current Australian tax system. Report for the Australian Government the Treasury, March, Canberra.
[108] Australian Bureau of Statistics (2016). Taxation Revenue, 2014-15, Cat. No. 5506DO001. ABS, Canberra, Australia.
[109] Australian Taxation Office 2018, Taxation Statistics 2015-16, available at: https://www.ato.gov.au/About-ATO/Research-and-statistics/In-detail/Taxation-statistics/Taxation-statistics---previous-editions/Taxation-statistics-2015-16/, accessed March 2019.

Table 4.11: Estimated lifetime deadweight losses from health system expenditure, new cases in 2019-20

	Federal gov.	State gov.	Total
Cost component ($m)	445.0	201.7	646.7
Rate of efficiency loss (%)	29.0	37.9	31.8
Deadweight loss ($m)	**129.1**	**76.4**	**205.5**

Source: Deloitte Access Economics estimates

The total annual deadweight losses associated with lost taxation as a result of reduced employment of people living with epilepsy is presented in Table 4.12. This amounts to $265.8 million in 2019-20, a figure comprised of $117.6 million attributable to the consumer, $110.7 million to employers (company) and $37.5 million to carers. The overall rate of efficiency loss is estimated to be 30.4%.

Table 4.12: Estimated annual deadweight losses from lost taxation, 2019-20

	Consumer	Company	Carer	Total
Cost component ($m)	496.2	217.8	158.0	872.0
Rate of efficiency loss (%)	23.7	50.8	23.7	30.4
Deadweight loss ($m)	**117.6**	**110.7**	**37.5**	**265.8**

Source: Deloitte Access Economics estimates

The estimated deadweight losses from lost taxation when extended over the lifetime of all people with newly diagnosed epilepsy in 2019-20 is presented in Table 4.13. This totals $616.1 million, with $161.4 million attributable to the consumer, $403.4 to employers (company) and $51.3 million to carers. The overall rate of efficiency loss is estimated to be 23.7%.

Table 4.13: Estimated lifetime deadweight losses from lost taxation, new cases in 2019-20

	Consumer	Company	Carer	Total
Cost component ($m)	679.7	1,699.4	215.9	2,595.0
Rate of efficiency loss (%)	23.7	50.8	23.7	23.7
Deadweight loss ($m)	**161.4**	**403.4**	**51.3**	**616.1**

Source: Deloitte Access Economics estimates

4.6 Summary – Other financial costs

In 2019-20, it has been estimated that other financial costs amount to $3,604.9 million in 2019-20 and $6,230.1 million when extended over the lifetime of newly diagnosed cases of epilepsy in 2019-20 (see Table 4.14 below).

Table 4.14: Summary of other financial costs, 2019-20

Cost component	Annual costs ($m)	Lifetime costs ($m)
Productivity	2,326.6	4,086.6
Informal care	438.2	598.8
Equipment	8.6	6.7
Transport	9.9	20.8
Deadweight loss	821.6	1,517.2
Total	**3,604.9**	**6,230.1**

Source: Deloitte Access Economics estimates

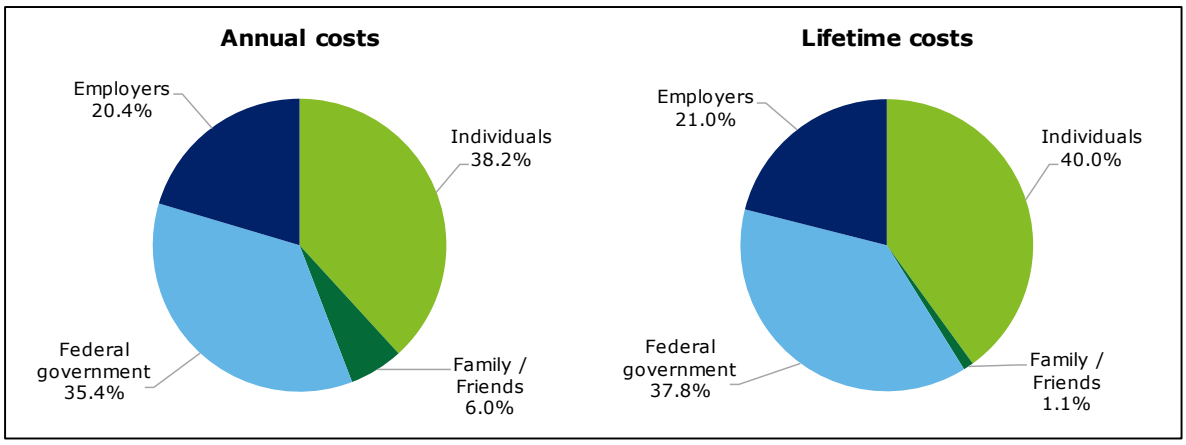
Overall, the burden of annual and lifetime other financial costs have been estimated to largely fall on individuals and the commonwealth government, as summarised in Table 4.15 and Figure 4.1. Specifically, individuals bear 38.2% of other financial costs in 2019-20 annual terms and 40.0% of other financial costs over the lifetime of new cases in 2019-20. Employers bear approximately one-fifth of annual and lifetime costs, resulting from productivity losses from epilepsy. Finally, the federal government is estimated to bear around 35.4% of annual costs, and 37.8% of lifetime costs, while the remaining 6.0% of annual costs and 1.1% of lifetime costs are borne by the family and friends of people living with epilepsy.

Table 4.15: Proportion of other financial costs of epilepsy by cost bearer, annual and lifetime 2019-20

Cost bearer	Annual costs ($m)	% of total costs	Lifetime costs ($m)	% of total costs
Individuals	1,377.8	38.2	2,492.7	40.0
Family/Friends	214.6	6.0	70.5	1.1
Federal government	1,277.3	35.4	2,355.8	37.8
Employers	735.2	20.4	1,311.1	21.0
Total	**3,604.9**	**100**	**6,230.1**	**100.0**

Source: Deloitte Access Economics estimates

Figure 4.1: Breakdown of other financial costs of epilepsy by cost bearer, annual and lifetime (2019-20)



Source: Deloitte Access Economics estimates

5 Burden of disease

Individuals experiencing epilepsy may suffer from loss of quality of life due to the pain, and disruption in day-to-day activities. These costs may be more important than health system costs or losses from reduced productivity.

This chapter presents a quantitative analysis of the loss of wellbeing and premature death both from epilepsy and other health conditions attributable to epilepsy. A disability adjusted life year (DALY) approach was taken to measuring the loss in the stock of health capital as a result of sleep disorders.

5.1 Methodology

The 'Burden of Disease' methodology developed by the WHO is a comprehensive measure of mortality and disability from diseases, injuries and risk factors for populations around the world in 1990, projected to 2020.[110] It uses a non-financial approach, where pain, suffering and premature mortality are measured in terms of Disability Adjusted Life Years (DALYs).

DALYs are a measurement unit that quantify the morbidity aspect and premature death associated with various diseases and injuries.[111] DALY weights are measured on a scale of zero to one, where a zero represents a year of perfect health and a one represents death. Other health states are given a weight between zero and one to reflect the quality of life that is lost due to a particular condition. For example, a disability weight of 0.2 is interpreted as a 20% loss in the quality of life relative to perfect health. Disability weights are determined by a reference group convened at the WHO on the basis of a person trade-off method for measuring health state preferences.[112]

Under the DALY framework, the total burden of disease for an individual with a condition is the sum of the mortality and morbidity components associated with that condition over time, including:

- The years of healthy life lost due to disability (YLDs)
- The years of healthy life lost due to premature death (YLLs)

Incorporating time preference for health (and thus discounting), this is represented by:

$$DALY_i = \sum_{t=a}^{a+L} \frac{Dw_{i,t}}{(1+r)^{t-a}}$$

where Dw is the DALY weight of the condition experienced by individual i, L is the residual life expectancy of the individual at age a, and t represents individual years within that life expectancy.

The total burden of disease from a condition on society can be calculated by aggregating DALYs of all individuals with the condition, which can be represented by:

$$DALY_i = \sum_{i=0}^{N_i} DALY_{i,t}$$

where N is the prevalence of the condition at time t.

5.2 Disability and mortality for epilepsy and attributable health conditions

5.2.1 Disability and mortality for epilepsy

The following data sources were consulted, in selecting an appropriate disability weight for epilepsy:

- Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011 (AIHW, 2016).[113]

[110] Murray, C.J. and Lopez, A.D., 1997. Alternative projections of mortality and disability by cause 1990–2020: Global Burden of Disease Study. *The Lancet*, 349(9064), pp.1498-1504.
[111] Murray, C.J. and Acharya, A.K., 1997. Understanding DALYs. Journal of health economics, 16(6), pp.703-730.
[112] Ibid.
[113] Australian Institute of Health and Welfare, 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. *Australian Burden of Disease Study series no. 3. Cat. no. BOD 4*.

- Global Burden of Disease Study 2016 (The Lancet, 2017).[114]
- Disability weights for the Global Burden of Disease Study 2013 (The Lancet, 2015).[115]

Table 5.1 summarises the published disability weights for epilepsy and their respective methodologies based on the studies above.

Table 5.1: Disability weights for epilepsy

Study	Disability weight	Method
Australian Burden of Disease Study (AIHW, 2016)	**0.222**	• Based on Australian data. • Disability weight derived by dividing YLDs of 33,738 by prevalence of 151,700.
Global Burden of Disease Study 2016 (The Lancet, 2017)	**0.335** (epilepsy as a sequelae of other health conditions) **0.282** (all causes)	• Based on 195 countries and territories. • Disability weight derived by dividing YLDs by estimated global prevalence and incidence rates
Global Burden of Disease Study 2013 (The Lancet, 2015)	**0.263** (Less severe epilepsy) **0.552** (More severe epilepsy)	• Disability weight provided based on four European countries (Hungary, Italy, the Netherlands, and Sweden) combined with previous 2010 Global Burden of Disease data.

Of the three studies reviewed, only the Global Burden of Disease Study 2013 directly provided a disability weight. In this case, the disability weight was estimated using survey participants aged 18 to 64 years from four European countries (Hungary, Italy, the Netherlands and Sweden) in combination with data from the Global Burden of Disease Study 2010.[116] For this study, the disability weighting was reported as 0.263 for less severe cases of epilepsy, and 0.552 for more severe cases.

The other two studies, published by The Lancet (2017) and AIHW (2016), provided prevalence estimates of epilepsy and the total years of life lived with the disability (YLDs). From this, a corresponding disability weight can be calculated by dividing epilepsy YLDs by the estimated prevalence.

The Lancet (2017) reported a global prevalence of epilepsy as approximately 23.9 million, with corresponding YLDs of 15.4 million. When epilepsy as a sequelae of other conditions is included, the estimated global prevalence climbs to 46 million, with YLDs of 15.4 million. As such, the estimated disability weights range from 0.28 to 0.34 (for epilepsy as a sequelae of other diseases).

The final study, published by the AIHW (2016) reported the total YLDs from epilepsy in Australia as being 33,738.[117] The corresponding prevalence figure in 2010-11 was estimated to be 151,800, giving a disability weight of 0.222. This disability weighting from AIHW is lower than the weight reported in the global burden of disease study, possibly due to the relatively higher burden

[114] Vos, T., Abajobir, A.A., Abate, K.H., Abbafati, C., Abbas, K.M., Abd-Allah, F., Abdulkader, R.S., Abdulle, A.M., Abebo, T.A., Abera, S.F. and Aboyans, V. (2017). Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*, 390(10100), pp.1211-1259.
[115] Salomon, J.A., Haagsma, J.A., Davis, A., de Noordhout, C.M., Polinder, S., Havelaar, A.H., Cassini, A., Devleesschauwer, B., Kretzschmar, M., Speybroeck, N. and Murray, C.J. (2015). Disability weights for the Global Burden of Disease 2013 study. *The Lancet*, 3(11), pp.e712-e723.
[116] Murray, C. J. L., Vos, T., Lozano, R., Naghavi, M., & Flaxman, A. D. (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, 380(9859): 2197-2223.
[117] Australian Institute of Health and Welfare, 2016. Australian Burden of Disease Study: Impact and causes of illness and death in Australia 2011. *Australian Burden of Disease Study series no. 3. Cat. no. BOD 4*.

experienced globally than in Australia. As such, the disability weight of 0.222 reported by AIHW was selected for this study to estimate the burden of disease of epilepsy in Australia in 2019-20.

The years of life lost (YLLs) for epilepsy were obtained from the Australian Burden of Disease Study, which provided preliminary estimates on YLLs due to epilepsy.[118] According to Epilepsy Australia, the most likely causes of death for people living with epilepsy are accidents, drowning, suicide and status epilepticus.[119] In 2015, it was estimated that 322 deaths were attributable to epilepsy. This figure was inflated to 2019-20 using the estimated prevalence of epilepsy generated for this report, as discussed in 2.1, giving an estimated 342 deaths attributable to epilepsy in 2019-20.

5.2.2 Disability and mortality for attributable health conditions

Burden of disease costs also included costs of additional health conditions that are directly attributable to epilepsy. As outlined in Appendix B, population attributable fractions (PAFs) were estimated and applied to the burden of additional health conditions. It should be noted that a wide range of comorbid health conditions were considered in the estimates of burden. However, the costs of these additional health conditions were only included if the evidence suggested a causal link between epilepsy and the condition. As such, the health conditions considered as being attributable to epilepsy, and therefore included in the analysis, are:

- depression and anxiety
- fractures
- cardiovascular disease
- sleep disorders

The disability weights for these other health conditions were derived based on the average disability weight implied by the total YLDs divided by the prevalence of each disease in The Lancet (2017) Global Burden of Disease Study 2016.[120] The disability weights for sleep disorders were obtained from the Deloitte Access Economics (2011) economic cost of sleep disorders study.[121] Specifically, the disability weights for the three sleep disorders – obstructive sleep apnoea, insomnia and restless leg syndrome – were averaged.

As the number of epilepsy-related deaths are likely to cover deaths by suicide and accidents, mortality associated with depression, anxiety and falls (unintentional injuries) are not included in the YLLs, to avoid double counting. Deaths associated with sleep disorders are not included, as sleep disorders are unlikely to contribute directly to premature mortality and only first-order impacts are considered.[122]

The only health condition where additional YLLs were considered was for cardiovascular defects and diseases. Applying the estimated PAF (0.42%) for cardiovascular disease to the YLLs for this specific health condition resulted in a total number of epilepsy-related deaths of 342.[123]

Table 5.2 shows the total prevalence of epilepsy and its associated health conditions, along with the estimated YLDs and YLLs. The total YLDs for epilepsy and associated health conditions are estimated to be 33,280 in 2019-20, and YLLs totalled 7,387.

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[118] Australian Institute of Health and Welfare (2015), Australian Burden of Disease Study 2015: fatal burden preliminary estimates, May 218, Canberra.
[119] Epilepsy Australia 2018, *Epilepsy and risk*, Available at: http://www.epilepsyaustralia.net/epilepsy-and-risk/, accessed March 2019.
[120] Vos, T., Abajobir, A.A., Abate, K.H., Abbafati, C., Abbas, K.M., Abd-Allah, F., Abdulkader, R.S., Abdulle, A.M., Abebo, T.A., Abera, S.F. and Aboyans, V. (2017). Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*, 390(10100), pp.1211-1259.
[121] Deloitte Access Economics 2011, Re-awakening Australia: The economic cost of sleep disorders in Australia, 2010. A report prepared for the Sleep Health Foundation Australia.
[122] In 2009, there were 19 deaths with the primary cause recorded as a sleep disorder (ABS 2011e). Together, these people cost 157 years of life, suggesting that they were on average over the age of 70.
[123] Zack, M. and Luncheon, C. (2018). Adults with an epilepsy history, notably those 45–64 years old or at the lowest income levels, more often report heart disease than adults without an epilepsy history. *Epilepsy & Behavior*, 86: 208-210.

Table 5.2: Estimated prevalence, YLDs and YLLs for epilepsy and attributable health conditions

Health condition	Prevalence	YLDs	YLLs
Epilepsy	142,740	31,688	7,190
Other health conditions (attributable to epilepsy)	18,431	1,592	197
Total	**161,171^**	**33,280**	**7,387**

Note: Prevalence for other health conditions are attributed to epilepsy by multiplying each condition's prevalence with the relevant PAF estimated in Appendix B. The disability weight for other health conditions is a weighted average of the prevalence and PAFs for each condition, which were estimated individually and summed up to derive the total YLDs and YLLs.

^Note: Epilepsy prevalence is estimated to be 142,740 in 2019-20, and within this same cohort around 18,431 (13%) individuals are estimated to have other health conditions as a result of epilepsy.

5.3 Converting DALYs to costs

Typically, a value of a statistical life year (VSLY) is derived from estimates of a willingness to pay for a reduction in the risk of physical harm in the context of operational health and safety (OHS) policy, transport and airspace regulation and environmental policy. The VSLY essentially estimates how much society is willing to pay to reduce the risk of premature death, expressed in terms of a saving a statistical life year. The VSLY based on 2014 guidance from the Department of Prime Minister and Cabinet was $182,000 per VSLY.[124] Inflating the figures to 2019-20 based on the CPI, the appropriate VSLY is $202,356.

The cost of the burden of disease due to epilepsy consists of the burden associated with YLDs and YLLs, and the value society places on a year of perfect health. Using the estimated VSLY, the total annual cost was estimated to $8,229.4 million for epilepsy and associated health conditions. Lifetime costs were estimated to be $15,904.7 million. This is not a direct cost to the economy in the traditional sense (i.e. a loss in productivity). It is the value of a loss in the stock of health capital.

Lifetime costs for burden of disease were estimated by assuming a disability weight for epilepsy and for associated health conditions, which were then multiplied by the value of a statistical life year and the number of estimated incident cases or 2019-20. The lifetime costs, which were discounted at 3%, represent the net present value of burden of disease costs for the incident epilepsy cases in 2019-20.

5.4 Summary – Burden of disease

Table 5.3shows that the annual costs of burden of disease is $8,229.4 million and lifetime costs is $15,094.7 million in 2019-20. The costs associated with burden of disease is completely borne by individuals with epilepsy.

Table 5.3: Summary of burden of disease, 2019-20

Component	Annual costs ($m)	Lifetime costs ($m)
Epilepsy	7,867.3	14,383.3
Associated conditions	362.1	711.4
Total	**8,229.4**	**15,094.7**

Source: Deloitte Access Economics estimates

[124] Department of the Prime Minister and Cabinet (2014), Best Practice Regulation Guidance Note: Value of statistical life, Dec 2014, Canberra.

6 Summary of costs

6.1 Annual cost of epilepsy in 2019-20

Epilepsy imposes a significant burden in Australia, spanning the healthcare system, quality of life of people living with the condition, workforce productivity for those with epilepsy and for the many people who provide care to them on an informal basis, as well as other financial costs. Overall, the total annual cost of epilepsy in 2019-20 was $12.3 billion for the 142,740 people living with active epilepsy in Australia in 2019-20.

This report found that epilepsy is costing Australia's health system $557.1 million, representing 14% of the total financial costs of epilepsy in 2019-20. The largest contributors to this are medication costs ($262.1 million) and acute hospital care costs ($169.8 million).

In addition to these substantial health system costs, epilepsy also imposes a burden through losses of productivity. These costs account for 60% of the total financial costs relating to epilepsy, totalling $2.33 billion. The cost of informal care provision to people living with epilepsy was estimated to be $438.2 million, based on the opportunity cost of carers' time. Finally, deadweight losses accounted for $821.6 million of the total annual financial costs, while equipment and transport comprised the residual at $8.6 million and $9.9 million, respectively.

Outside of the financial costs, epilepsy was estimated to cost Australia $8.2 billion in 2019-20, based on the value of a statistical life years (VSLY). These costs are summarised in Table 6.1.

Table 6.1: Total annual costs associated with epilepsy in Australia 2019-20

Cost component	Annual cost ($m)	% of total cost
Health system	557.1	4.5
Productivity	2,326.6	18.9
Informal care	438.2	3.6
Equipment	8.6	0.1
Transport	9.9	0.1
Deadweight losses	821.6	6.7
Total financial costs	**4,162.0**	**33.7**
Loss of wellbeing (non-financial)	**8,172.2**	**66.3**
Total costs (financial and non-financial)	**12,334.2**	**100.0**

Source: Deloitte Access Economics estimates

These estimated costs are comparable to many other health conditions, demonstrating the significance of epilepsy in terms of its annual burden in Australia. For example, epilepsy is estimated to impose a greater burden on Australia's health system than prostate cancer ($0.5 billion) and a burden similar to that of lung cancer ($0.6 billion).[125]

Furthermore, the estimated burden of disease of epilepsy is comparable to that of Parkinson's disease. In 2011, it was found that the burden of disease of this common neurological condition was

[125] Cancer Council 2019, Cancer costs Australian health services over $6 billion a year: new research, available at: https://www.cancercouncil.com.au/media-release/cancer-costs-australian-health-services-6-billion-year-new-research/, accessed April 2019.

$7.6 billion. This equates to approximately $8.8 billion when inflated to 2019;[126] the equivalent figure for epilepsy is $8.2 billion, as per Table 6.1.

Table 6.2 provides a breakdown of the total annual cost of epilepsy in 2019-20 by state and territory.

Table 6.2: Total annual cost of epilepsy, by state and territory, 2019-20

Jurisdiction	Total cost ($m)
NSW	3,946.1
VIC	3,206.8
QLD	2,473.1
WA	1,272.9
SA	847.2
TAS	257.8
ACT	208.2
NT	122.2
Total (financial and non-financial)	**12,334.2**

Source: Deloitte Access Economics estimates

6.2 Lifetime cost of epilepsy

In total, there are an estimated 14,603 new cases of epilepsy across Australia in 2019-20. When the cost of these cases is projected over their lifetime, the estimated total cost to Australia is $22.2 billion. Of this, $7.1 billion are financial costs, while non-financial costs related to losses of wellbeing account for the remaining $15.1 billion.

These lifetime costs are distributed in a similar manner to the annual cost as discussed in Section 6.1. Health system costs are significant, costing Australia $897.6 million, with the largest costs again accounted for by medication costs ($587.9 million) and acute hospital care costs ($114.3 million).

In addition to these substantial health system costs, epilepsy also imposes a burden through losses of productivity. These costs account for 60% of the total financial costs relating to epilepsy, totalling $4.1 billion. The cost of informal care provision to people living with epilepsy was estimated to be $598.8 million, based on the opportunity cost of carers' time. Finally, deadweight losses accounted for $1.5 billion, equipment $6.7 million, and transport costs for $20.8 million. Lifetime equipment costs are lower than annual costs as equipment costs are not incurred in every year of the individual's life.[127] Outside of the financial costs, epilepsy was estimated to cost Australia $15.1 billion in 2019-20, based on the value of a statistical life year (VSLY). These costs are summarised in Table 6.3.

[126] Deloitte Access Economics 2011, Living with Parkinson's disease - update, available at: https://www2.deloitte.com/au/en/pages/economics/articles/living-with-parkinsons-disease.html, accessed April 2019.

[127] It has been assumed that the cost is only incurred every three years. Discounting the future costs of equipment through the number of new epilepsy cases in 2019-20 has resulted in a lower cost than the corresponding prevalence estimates.

Table 6.3: Total lifetime costs associated with new epilepsy cases in Australia in 2019-20

Cost component	Lifetime cost ($m)	% of total cost
Health system	897.6	4.0
Productivity	4,086.6	18.4
Informal care	598.8	2.7
Equipment	6.7	0.0
Transport	20.8	0.1
Deadweight losses	1,517.2	6.8
Total financial costs	**7,127.7**	**32.1**
Loss of wellbeing (non-financial)	**15,094.7**	**67.9**
Total costs (financial and non-financial)	**22,222.4**	**100.0**

Source: Deloitte Access Economics estimates

Table 6.4 provides a breakdown of the total lifetime cost of new epilepsy cases in 2019-20 by state and territory.

Table 6.4: Total lifetime cost of epilepsy, by State and Territory

Jurisdiction	Lifetime cost ($m)
NSW	7,109.6
VIC	5,777.7
QLD	4,455.7
WA	2,293.3
SA	1,526.4
TAS	464.4
ACT	375.2
NT	220.2
Total	**22,222.4**

Source: Deloitte Access Economics estimates

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Appendix A – Health costs

Table A.1: Estimated number of hospital separations related to epilepsy by jurisdiction, 2019-20

State	Acute separations	Sub-acute and non-acute separations
NSW	9,978	577
VIC	8,109	469
Qld	6,253	362
SA	2,142	124
WA	3,219	186
TAS	652	38
NT	309	18
ACT	527	30
National	**31,194**	**1,804**

Note: The state-specific values may not sum to total due to a small exclusion of separation numbers of some territories.

Table A.2: Estimated hospitalisation costs by jurisdiction, 2019-20

Jurisdiction	Average cost per weighted acute separation ($)	Average cost per weighted sub-acute or non-acute separation ($)	Total acute separation costs ($ million)	Total sub-acute and non-acute separation costs ($ million)
NSW	5,342	9,649	53.3	5.9
VIC	4,900	14,940	39.7	7.4
Qld	5,344	14,830	33.4	5.6
SA	5,922	14,546	12.7	1.9
WA	6,942	33,428	22.3	6.6
TAS	5,569	19,394	3.6	0.8
NT	6,935	52,625	2.1	1.0
ACT	5,909	14,122	3.1	0.5
National	**5,444**	**13,997**	**169.8**	**29.5**

Source: IPHA (2019) and AIHW (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices

Table A.3: Estimated outpatient costs related to epilepsy by jurisdiction, 2019-20

Jurisdiction	Events related to epilepsy	Average cost ($)	Total non-admitted cost ($ million)
NSW	33,852	241	8.2
VIC	15,549	363	5.6
Qld	23,097	353	8.2
SA	7,296	441	3.2
WA	9,424	384	3.6
TAS	1,971	325	0.6
NT	1,511	540	0.8
ACT	4,138	298	1.2
National	**96,838**	**325**	**31.5**

Source: IPHA (2019) and AIHW (2018). A growth rate of 4.1% annually is applied to project the number of events in 2016-17 to 2019-20. A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices. Note: Non-admitted events only available for public hospitals, a ratio of 0.7 was applied to estimate the number of non-admitted events at private hospitals. This rate was based on the ratio of public to private hospital separations.

Table A.4: Estimated GP costs related to epilepsy treatment by jurisdiction, 2019-20

Jurisdiction	Average cost ($)	Number of GP Visits (Epilepsy related)	Total cost (Epilepsy related) ($ million)
NSW	51.3	150,593	7.72
VIC	53.0	121,357	6.43
QLD	53.7	94,840	5.09
SA	53.1	33,145	1.76
WA	54.0	48,600	2.62
TAS	56.2	10,263	0.58
NT	54.5	4,417	0.24
ACT	66.2	7,734	0.51
National	**52.9**	**471,043**	**24.92**

Source: Department of Health Medicare Statistics (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

Table A.5: Estimated pathology and imaging costs related to epilepsy (non-hospital), 2019-20

Jurisdiction	Number of GP Visits (Epilepsy related)	Number of imaging test orders	Number of pathology test orders	Average cost per imaging test ($)	Average cost per pathology test ($)	Total cost for pathology and imaging tests ordered ($ million)
NSW	150,593	15,963	68,520	128	19	3.4
VIC	121,357	12,864	55,217	119	18	2.6
QLD	94,840	10,053	43,152	125	20	2.1
SA	33,145	3,513	15,081	121	17	0.7
WA	48,600	5,152	22,113	123	19	1.1
TAS	10,263	1,088	4,670	119	17	0.2
NT	4,417	468	2,010	113	20	0.1
ACT	7,734	820	3,519	125	19	0.2
National	**471,043**	**49,931**	**214,324**	**124**	**19**	**10.4**

Source: Department of Health Pathology and Diagnostics Imaging Statistics (2018). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices.

Table A.6: Estimated pharmaceutical costs related to epilepsy (non-hospital), 2019-20

Jurisdiction	Number of patients who use AED	Average cost ($)	Total cost ($ million)
NSW	43,574	1,700	83.8
VIC	35,115	1,700	67.5
QLD	27,442	1,700	52.8
SA	9,590	1,700	18.4
WA	14,063	1,700	27.0
TAS	2,970	1,700	5.7
NT	1,278	1,700	2.5
ACT	2,238	1,700	4.3
National	**136,297**	**1,700**	**262.1**

Source: Epilepsy Foundation Longitudinal Survey of People with Epilepsy Wave 3 (2014) and Pharmaceutical Benefits Scheme Statistics (2019). A health inflation rate of 1.7% annually is applied to inflate costs to 2019-20 prices. The average annual costs was assumed to be the same across all jurisdictions.

Table A.7: Estimated research funding related to epilepsy, 2019-20

Jurisdiction	Total research funding ($million)
NSW	1.79
VIC	23.34
QLD	1.32
SA	1.62
WA	0.34
TAS	0.25
NT	1.79
ACT	0.16
National	28.82

Source: National Health and Medical Research Council (NHMRC), 2018, All Grants 2000-2016. Research Funding Statistics and Data.

Table A.8: Estimated healthcare expenditure on epilepsy by component, 2019-20 ($ millions)

State	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	Aust
Hospital	59.2	47.1	39.1	14.6	28.9	4.4	3.1	3.6	199.4
Outpatient	8.2	5.6	8.2	3.2	3.6	0.6	0.8	1.2	31.5
Primary	7.7	6.4	5.1	1.8	2.6	0.6	0.2	0.5	24.9
Pathology & imaging	3.4	2.6	2.1	0.7	1.1	0.2	0.1	0.2	10.4
Pharmaceuticals	83.8	67.5	52.8	18.4	27.0	5.7	2.5	4.3	262.1
Research	1.8	23.3	1.3	1.6	0.3	0.2	1.8	0.2	28.8
Total	164.0	152.6	108.5	40.3	63.6	11.8	8.5	9.9	557.1

Appendix B – Population attributable fractions

Population attributable fractions (PAFs) reflect the proportion of a specific injury, health condition or disease that can be directly attributable to epilepsy. This section estimates the PAFs for epilepsy based on literature review findings on epilepsy prevalence rates and the link between epilepsy and other health conditions. PAFs have been applied to the cost estimates for healthcare, productivity and burden of disease to obtain estimates of related health conditions that are linked to epilepsy.

B.1. Methodology

A literature review was conducted to examine what other conditions typically accompanied epilepsy. Where the literature indicated that epilepsy increased the risk of another health condition, the risk ratio for that study was obtained. A PAF for each specific condition was calculated using the following equation, which was taken from Eide and Heuch (2001):[128]

$$PAF = \frac{s_1.(RR-1)}{s_1.(RR-1)+1}$$

Where:

$s_1 = prevalence\ of\ epilepsy$

$RR = relative\ risk\ ratio$

Where only the odds ratio (OR) was reported, these were converted into relative risks using the prevalence rate of that specific condition and the odds ratio. The formula to convert the OR into a RR is:

$$RR = \frac{OR}{1-s_2+(s_2.OR)}$$

Where:

$s_2 = prevalence\ of\ the\ health\ condition$

In studies where a prevalence ratio was reported, it was assumed that the prevalence ratio is an approximation of the RR.[129]

The PAFs considered for this study include:

- depression and anxiety
- fractures
- motor vehicle accidents
- cardiovascular disease
- sleep disorders
- neurodevelopmental disorders (including attention deficit hyperactivity, autism, cerebral palsy and intellectual disability)
- migraines

[128] Eide, GE, Heuch, I 2001, 'Attributable fractions: fundamental concepts and their visualization', Statistical Methods in Medical Research, 10: 159-193.

[129] The prevalence ratio is the prevalence of an outcome (e.g. sleep disorders) in individuals with epilepsy, and the prevalence of that outcome in individuals without epilepsy. For instance, if the prevalence ratio of sleep disorders is 2.1, this was assumed to be analogous to the relative risk, and used in calculating the population attributable fraction.

This report only considered the 'first round' impact of epilepsy on other conditions, not the potential impact of these conditions on the risk of other conditions. When including further round effects there is a risk of double counting or incorrectly attributing costs to the original condition.

B.2. Depression and anxiety

Kanner (2006) noted that depression is one of the most common mental health co-morbidities in those diagnosed with epilepsy. Leaving depression untreated may lead to increased risk of suicide, and reduced quality of life. In addition to factors such as frequency of seizures, antiepileptic drug treatment may be associated with depression (Mula and Schmitz 2009).

In a meta-analysis examining prevalence of depression in persons diagnosed with epilepsy, the relative risk of depression (within the past 12 months of the study) is 2.58.[130] Based on a 12-month prevalence of depression of 4.1%,[131] **the corresponding PAF is 0.88%, suggesting that 0.88% of cases of depression is attributable to epilepsy.** In a population-based study in Canada, the relative risk of anxiety disorders is 2.31. This suggests **a PAF of 0.73% given a prevalence of generalised anxiety of 2.7%.[132]**

For this study, the PAFs for depression and anxiety (0.88% and 0.73%) were applied.

B.3. Fractures

Various studies have recognised the increased risk of fractures in patients with epilepsy. Mattson and Gidal (2004) note that patients with epilepsy are at two to six times higher risk, compared to the general population, of suffering from skeletal fractures.[133] Sheth, Gidal and Hermann (2006) reported that fracture rates amongst patient with epilepsy are two to three times higher than the general population.[134] The heightened risk of fractures could be due to seizures or falls, and side effects of antiepileptic drugs may also contribute to the risk for falls.

In a meta-analysis examining epilepsy on fracture risk and changes in bone mineral density, it was found that the RR of any fracture was 2.2; the RR of hip fractures was 5.3; forearm fractures 1.7 and spine fractures 6.2.[135] **Based on the RR of any fracture (2.2), the estimated PAF suggested that 0.67% of all fractures were attributable to epilepsy, which was used in this study.**

B.4. Motor vehicle accidents

In a systematic review, evidence of increased risk of motor vehicle accidents amongst drivers with epilepsy, compared with the general population, was mixed.[136] The authors found that a number of studies found a decreased or similar risk of motor vehicle accidents (MVA) compared to the general population, while other studies found a heightened risk of MVAs.

A recent study based on seizure-related vehicle crashes in Victoria, Australia, found that most of the injuries from seizure-related crashes were more severe than non-seizure related crashes.[137] The authors recommended that driver licensing authorities should include collision characteristics into

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[130] Fiest, K.M., Dykeman, J., Patten, S.B., Wiebe, S., Kaplan, G.G., Maxwell, C.J., Bulloch, A.G. and Jette, N., 2013. Depression in epilepsy: a systematic review and meta-analysis. *Neurology*, 80(6), pp.590-599.
[131] The Department of Health 2009. Affective, anxiety and substance use disorders in the Australian population. Accessed at http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-m-mhaust2-toc~mental-pubs-m-mhaust2-hig~mental-pubs-m-mhaust2-hig-aff
[132] Ibid.
[133] Mattson, R.H. and Gidal, B.E., 2004. Fractures, epilepsy, and antiepileptic drugs. *Epilepsy & Behavior*, 5, pp.36-40.
[134] Sheth, R.D., Gidal, B.E. and Hermann, B.P., 2006. Pathological fractures in epilepsy. *Epilepsy & Behavior*, 9(4), pp.601-605.
[135] Vestergaard, P., 2005. Epilepsy, osteoporosis and fracture risk–a meta-analysis. Acta Neurologica Scandinavica, 112(5), pp.277-286.
[136] Naik, P.A., Fleming, M.E., Bhatia, P. and Harden, C.L., 2015. Do drivers with epilepsy have higher rates of motor vehicle accidents than those without epilepsy?. *Epilepsy & Behavior*, 47, pp.111-114.
[137] Neal, A., Carne, R., Odell, M., Ballek, D., D'Souza, W.J. and Cook, M.J., 2018. Characteristics of motor vehicle crashes associated with seizure: Car crash semiology. Neurology, 91(12), pp.e1102-e1111.

the overall assessment of suspected seizure-related crashes. However, the study did not report any heightened risk of MVA due to epilepsy. The authors suggested that further research should examine restriction of driving after 'risk periods' as a harm-minimization strategy.

Due to the inconclusive evidence, costs associated with motor vehicle incidents were not included in the cost of epilepsy.

B.5. Cardiovascular disease

In a community-based study, Bardai et al (2012) assessed the risk for sudden cardiac arrest in patients with active epilepsy. Epilepsy was associated with a three-fold increased risk for sudden cardiac arrest, with some studies hypothesise that sudden unexpected death in epilepsy is a result from seizure-related sudden cardiac arrest.[138]

Based on the U.S. National Health Interview Survey, Zack and Luncheon (2018) noted that for those 18 years and older with a history of epilepsy reported heart disease about nine percentage points more than those without a history of epilepsy. Specifically, the study found that the relationship to be strongest between epilepsy and those in the 45-64 year age group and at the lowest household income levels.[139] **The associated RR of heart disease in epilepsy patients is 1.75, resulting in a PAF of 0.42%, which is used for this study across all age groups.**

B.6. Sleep disorders

The literature has established the relationship between sleep disorders and epilepsy. Bazil (2003) noted that sleep disruption is associated with antiepileptic drugs and the occurrence of seizures, with seizures potentially having an impact on sleep patterns beyond the postictal period (i.e. the period between the end of a seizure and return to the baseline condition).[140] Manni and Terzaghi (2010) noted evidence suggests obstructive sleep apnoea (OSA) is comorbid with epilepsy and that prevalence of OSA is potentially higher in drug-resistant epilepsy patients.[141]

Ottman et al (2010), who conducted a survey of the US population to screen for a lifetime history of epilepsy found that the prevalence ratio of sleep apnoea was 1.44.[142] **Assuming that the PR is analogous to the RR, a PAF of 0.25% was estimated and used in this study, indicating that around 0.26% of sleep apnoea cases are attributable to epilepsy.**

B.7. Neurodevelopment disorders

B.7.1. Attention deficit hyperactivity disorder

In a review of the relationship between attention deficit hyperactivity disorder (ADHD) and epilepsy, Williams et al (2016) noted that prevalence of ADHD in the general population of children is 7-9%. In children with epilepsy, ADHD was present in 20-50% of patients. The authors also found that children with complicated epilepsy have been found to be at higher risk for ADHD compared to those with uncomplicated epilepsy, and that there is some evidence that antiepileptic drugs can contribute to symptoms of ADHD.[143] However, the causality between epilepsy and ADHD has not been established: the evidence indicates that a correlation exists between both health conditions, however there is no longitudinal evidence providing a causal link between ADHD and epilepsy.

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B.7.2. Autism

The literature recognises that autism and epilepsy in children are highly comorbid (Viscidi et al 2013). The authors also note that individuals with autism spectrum disorder (ASD) and epilepsy have worse behavioural and social outcomes than those with ASD only.

The study by Viscidi et al (2013) examined the association between epilepsy and parent-reported autism symptoms and behaviors from three scales: the Social Responsiveness Scale (SRS), Repetitive Behaviour Scale–Revised (RBS-R), and Aberrant Behaviour Checklist (ABC). **After adjusting for age and gender, on average the relative risk for association between epilepsy and autism symptoms / maladaptive behaviours in children with ASD is 1.12, suggesting a PAF of 0.07%, which is used in this study.**

B.7.3. Cerebral palsy and intellectual disability

In studies that report the frequency of cerebral palsy in children diagnosed with epilepsy, the range was from 8% to 18%. The lower bound proportion is based on a study in the USA were 8% of incident epilepsy cases had co-diagnoses of mental retardation, cerebral palsy, or both, in children below 15 years of age with newly diagnosed epilepsy.[144] The mid-point estimate is based on a study in Finland, of children who were born in 1966 and followed-up until 16 years of age. Amongst children who had at least one instance of an epileptic seizure, the proportion who had cerebral palsy was 15.9%.[145] In a study based on children who were enrolled in the Metropolitan Atlanta Developmental Disabilities Study, the proportion of children diagnosed with epilepsy who had cerebral palsy was 18%.[146] The mean proportion of children with epilepsy who also had cerebral palsy, based on these studies, is 14.0%. However, these studies have not established a causal link between cerebral palsy, intellectual disability and epilepsy – only the correlation between these health conditions have been reported. The costs of cerebral palsy and intellectual disability have therefore not been included in the costs of epilepsy.

B.8. Migraine

Several studies recognise that migraine and epilepsy are highly comorbid. For instance, Kim and Lee (2017) note that both conditions may be triggered by a genetic predisposition and that some antiepileptic drugs are used for patients with migraine, as well as epilepsy.[147] Similarly, Nye and Thadani (2015) also noted that the two conditions may be triggered by genetic factors, and that medications to treat migraine are also administered to patients with epilepsy.[148] In a review of comorbidities of epilepsy, Ottman (2011) noted epilepsy and migraine may be triggered by genetic or environmental factors, such as a traumatic head injury.[149]

The review by Kim and Lee (2017), however, found that there was lack of evidence pointing to a causal relationship between headache and epilepsy, with further studies required to demonstrate the relationship between the two conditions.[150] In light of the lack of evidence causally linking migraine and epilepsy, costs associated with migraine were not included as part of final cost estimates.

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B.9. Summary of PAFs

A summary of the PAFs used to inform this study is summarised below in Table B.1.

Table B.1: Summary of PAFs used in this report

Comorbidity	Relative risk	Population attributable fraction	Author
Active depression	2.77	0.88%	Fiest et al 2013
Anxiety	2.31	0.73%	Tellez-Zenteno 2007
Fracture (all)	2.2	0.67%	Vestergaard et al 2005
Heart disease	1.75	0.42%	Zack and Luncheon (2018)
Sleep disorder and apnoea	1.44	0.25%	Ottman et al 2011

Source: Various sources and Deloitte Access Economics analysis.

Limitation of our work

General use restriction

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