



**Social and economic cost of eating disorders in the United States of America**

Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders

June 2020

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# Glossary

AHRQ	Agency for Healthcare Research and Quality
AN	Anorexia nervosa
ARFID	Avoidant restrictive food intake disorder
AWE	Average weekly earnings
BED	Binge-eating disorder
BLS	US Bureau of Labor Statistics
BMI	Body mass index
BN	Bulimia nervosa
CBT	Cognitive behavioral therapy
CPES	Collaborative Psychological Epidemiological Surveys
DALY	Disability adjusted life year
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating disorder
EDNOS	Eating disorder not otherwise specified
FBT	Family-based therapy
FPT	Focal psychodynamic therapy
GBD	Global Burden of Disease Study
GPIP	Group psychodynamic interpersonal psychotherapy
ICD	International Classification of Diseases
ICER	Incremental cost-effectiveness ratio
IOP	Intensive outpatient
MEPS	Medical Expenditure Panel Survey
NCS	National Comorbidity Survey
NESARC	National Epidemiologic Survey on Alcohol and Related Conditions
OSFED	Other specified feeding or eating disorder
PHP	Partial hospitalization program
SSDI	Social Security Disability Insurance
US	United States of America
VSL(Y)	Value of statistical life (year)
YLD	Years of healthy life lost due to morbidity
YLL	Years of life lost due to premature death



# Executive summary

## Background

Eating disorders (EDs) are a group of mental illnesses that can impact an individual and their family through complex mental and physical impairments. The main forms of EDs considered for this report include anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), and other specified feeding or eating disorders (OSFED).<sup>1</sup> The adverse physical consequences of dieting, weight loss and purging behaviors are notable and sometimes fatal.

The Strategic Training Initiative for the Prevention of Eating Disorders, based at the Harvard T.H. Chan School of Public Health and Boston Children's Hospital, and the Academy for Eating Disorders engaged Deloitte Access Economics to estimate the social and economic impact of EDs in the United States of America (US) in 2018-19.

The costs of EDs in the US were estimated from a societal perspective for the fiscal year between 1 October 2018 and 30 September 2019 (referred to as "2018-19" in this report) using cost-of-illness methods. Costs were estimated using a prevalence approach, where prevalence was estimated based on a combination of nationally representative surveys and modelling studies in the US. Costs were then primarily generated<sup>2</sup> by multiplying prevalence by mean incremental costs for people with EDs across a range of cost components, which included:

- **financial costs to the health system** (e.g. costs of providing care in hospital and residential treatment facilities, and visits to primary care provider and other health services).
- **productivity costs** from reduced workforce participation and reduced productivity at work, loss of future earnings due to premature mortality, and the value of informal care (lost productive income of caregivers who provide help to people with EDs).
- **other costs**, which include transfer costs, and their associated efficiency losses, or reduced economic efficiency, associated with the need to levy additional taxation to fund the provision of government services.

The **value of reduced wellbeing** for people with EDs was also estimated. While the loss of wellbeing is not a financial cost, reduced quality of life due to impaired functioning and premature death that result from EDs was measured in monetary terms by multiplying a value of a statistical life year (VSLY) by the years of healthy life lost using the burden of disease methodology.<sup>3</sup>

Inputs for this modelling study were largely drawn from previous academic literature where greater emphasis was placed on nationally representative studies (e.g. rather than studies in insured populations alone).

## Prevalence and mortality

The overall one-year prevalence of EDs was estimated to be 1.66% in the US in 2018-19 (5.48 million cases). Prevalence was estimated to be higher in females (2.62%, 4.39 million cases) compared to males (0.67%, 1.09 million cases) (see Chart i). The most common ED was OSFED

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<sup>1</sup> EDs also include avoidant restrictive food intake disorder (ARFID), pica and rumination disorder. Each of these were excluded from the scope of the report as there are a lack of comprehensive economic data available for these conditions. OSFED is a clinically significant disturbance of eating behavior where the symptoms do not fulfill the criteria for other EDs.

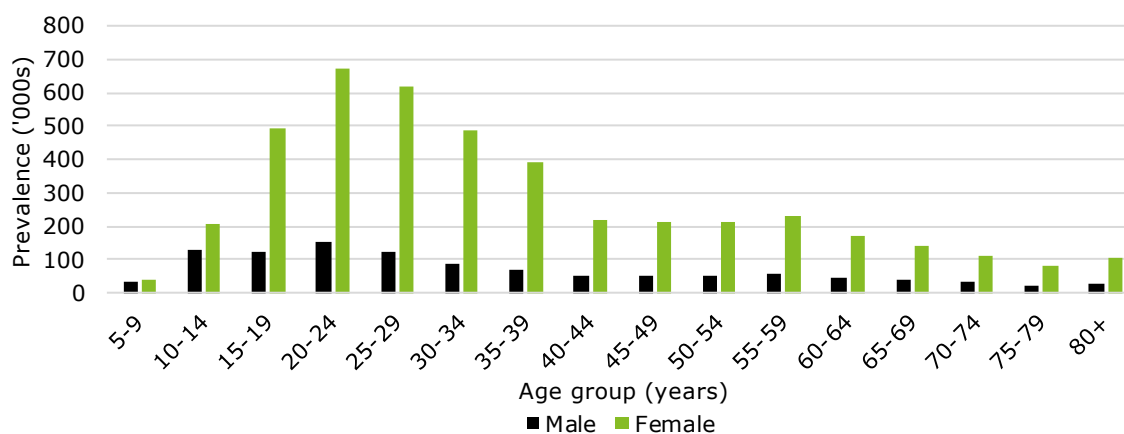
<sup>2</sup> Some costs were generated using a top-down approach, for example, by utilizing estimates of the total cost of care in hospital, or by modelling the costs of residential care based on the capacity of the system. Specific methodologies for each cost component have been described in more detail throughout the report.

<sup>3</sup> Years of healthy life lost are measured in DALYs and include both the years of healthy life lost due to morbidity (YLDs) and the years of life lost due to premature mortality (YLLs). The VSLY is the value that society places on an anonymous year of a person's life. It often represents the willingness to pay to avoid greater risk of mortality or impaired quality of life.

with a prevalence of 1.18% for females and 0.27% for males. Prevalence was highest among the 20-29 year old age group for both males and females.

The overall lifetime prevalence of EDs was estimated to be 8.60% among females and 4.07% among males. As with one-year prevalence, OSFED is the most common ED experienced over an individual’s lifetime with respective prevalence of 3.82% among females and 1.61% among males. Overall, it was estimated that 21.0 million people in 2018-19 have had an ED at some point in their lives, of which 14.4 million cases occurred in women and 6.6 million cases occurred in men.

Chart i: One-year prevalence of EDs in the US in 2018-19



Source: Deloitte Access Economics analysis.

Based on current lifetime prevalence, incidence and mortality data, it was estimated that **28.8 million Americans alive in 2018-19 will have an ED at some point during their life** – either in the past, present or future. As 21.0 million people have had an ED during their life (past and present), 7.8 million Americans alive in 2018-19 will develop an ED in the future. Of these new cases in the future, approximately 1.9 million will occur in children and adolescents before they are 20 years old.

Evidence suggests that EDs are associated with **substantial excess premature mortality**.<sup>4</sup> An authoritative meta-analysis found that mortality rates were 5.86 times higher than the general population in people with AN, 1.93 for BN, and 1.92 for eating disorder not otherwise specified (EDNOS).

When these rates were applied in the modelling, it was estimated that approximately 10,200 deaths (ranging between 5,500 and 22,000 deaths) were associated with EDs in 2018-19.<sup>5</sup> More deaths were associated with OSFED (approximately 3,400 deaths or 33% of the total deaths due to EDs) than any other ED, noting the greater prevalence of the condition driving that result.

### Costs of EDs

The total financial costs associated with EDs were estimated to be \$64.7 billion in 2018-19, which equates to \$11,808 per person with an ED. In addition, EDs are also associated with a substantial reduction in wellbeing among people with EDs, which resulted in a further (non-financial) value of \$326.5 billion. These costs are summarized by cost component in Table i, and by age and gender in Chart ii.

<sup>4</sup> Official mortality estimates may understate the true number of deaths due to EDs. EDs often go undetected and undiagnosed, and the cause of death among individuals with an ED may be recorded as some other factor (for example, heart failure) rather than the underlying disorder, here an ED.

<sup>5</sup> The SMRs published by Arcelus et al. (2011) do not all control for confounding factors (for example, comorbid conditions) which may result in higher mortality rates for individuals with EDs. Therefore, this estimated mortality reflects the estimated deaths associated with EDs rather than only those deaths which are due to an underlying cause of ED.

Some scholars caution against including efficiency losses – the costs associated with the act of taxation and transfers, which distorts incentives and results in inefficiencies in the economy – and argue that they are not valid, but others support their inclusion, since in their absence, the associated costs and the potential benefits of prevention and treatment would be underestimated (see section 4.4). Excluding efficiency losses, the total financial costs would be \$59.9 billion.

Table i: Total costs associated with EDs, 2018-19

Cost component	Total cost (\$m)	Per person (\$)	Proportion of financial costs (%)
Health system	4,555.4	831	7.0%
Productivity losses	48,634.3	8,874	75.2%
Informal care	6,731.4	1,228	10.4%
Efficiency losses	4,794.8	875	7.4%
<b>Total financial costs</b>	<b>64,716.0</b>	<b>11,808</b>	<b>100.0%</b>
<b>Loss of wellbeing (non-financial)</b>	<b>326,530.2</b>	<b>59,579</b>	

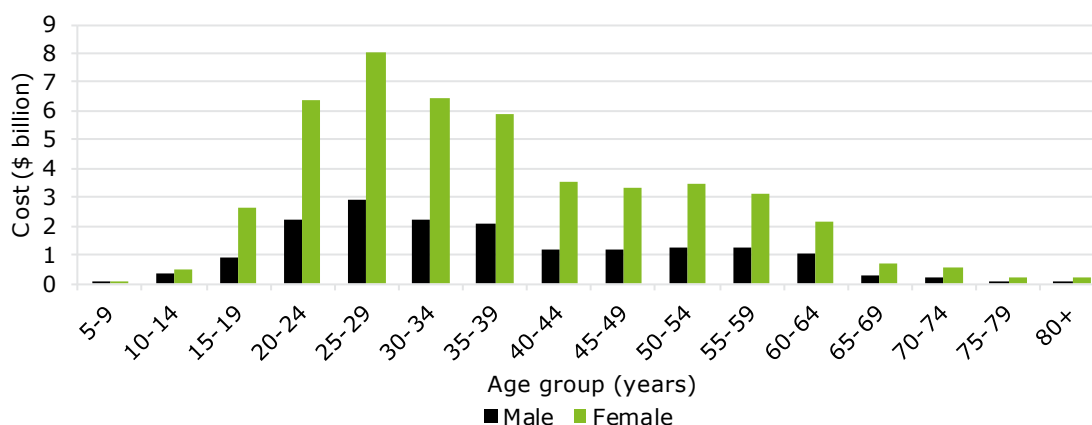
Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

Of total financial costs (\$64.7 billion), health system costs made up 7.0% of the total, accounting for \$4.6 billion. Of this expenditure, \$363.5 million was paid by Americans in out-of-pocket costs to manage their ED.

Productivity costs make up the largest share of total financial costs (75.2%) while efficiency losses account for 7.4%. Informal care, which is care given free of charge, accounted for the remaining 10.4% of financial costs attributed to EDs in 2018-19 (measured as the caregivers’ forgone labor earnings). It was estimated that government bore 27.5% of total financial costs, with the remaining costs shared across individuals (29.0%), employers (25.2%), society and other payers (11.0%), and family or friends (7.3%).

EDs were associated with 1.3 million disability adjusted life years (DALYs) in 2018-19, which, using the VSLY to enumerate DALYs in dollar terms, represents a (non-financial) value of \$326.5 billion.

Chart ii: Total financial costs associated with EDs by age and gender, 2018-19, \$ billions



Source: Deloitte Access Economics analysis.

### Sensitivity analysis

One-way sensitivity analyses were conducted to estimate an upper and lower bound for estimates, including on the mortality, prevalence, health system, productivity, efficiency losses, and VSLY parameters. The upper and lower scenario for these variables was informed based on available estimates published in the literature, such as the published confidence interval or standard error around estimates.

The results of one-way sensitivity analyses indicated a wide degree of potential variance in the estimates. Under the low case (all parameters were set to their lowest impact) and high case (all parameters were set to their highest impact) scenarios, total financial costs were estimated to range from \$10.6 billion to \$232.8 billion respectively in 2018-19, with the value of reduced wellbeing ranging from \$21.8 billion to \$1.4 trillion respectively. Total financial costs were found to vary most substantially with changes in prevalence, followed by changes in productivity.

Table ii: Total costs associated with EDs (\$ billions), 2018-19

Sensitivity analysis	Relative variation from base case	Health system	Productivity	Other financial costs	Total financial costs	Loss of wellbeing
<b>High combined</b>	-	9.8	186.1	36.9	232.8	1,442.6
<b>Low combined</b>	-	1.9	5.5	3.2	10.6	21.8
<b>Prevalence</b>						
Upper	198%	8.2	96.3	22.7	127.3	646.8
Lower	40%	2.3	19.6	4.7	26.7	131.8
<b>Mortality</b>						
Upper	166%	4.6	58.4	12.2	75.2	400.5
Lower	76%	4.6	44.6	11.2	60.4	297.0
<b>Health system</b>						
Upper	119%	5.4	48.6	11.6	65.7	326.5
Lower	81%	3.7	48.6	11.4	63.7	326.5
<b>Productivity</b>						
Upper	175%	4.6	84.1	14.2	102.9	326.5
Lower	25%	4.6	17.6	9.1	31.2	326.5
<b>Productivity</b>						
Upper	150%	4.6	72.0	13.3	89.9	326.5
Lower	50%	4.6	27.2	9.9	41.7	326.5
<b>Productivity</b>						
Upper	125%	4.6	60.1	12.4	77.1	326.5
Lower	75%	4.6	37.6	10.7	52.9	326.5
<b>Efficiency losses</b>						
Upper	145%	4.6	48.6	13.7	66.9	326.5
Lower	40%	4.6	48.6	9.6	62.8	326.5
<b>VSLY</b>						
Upper	182%	4.6	48.6	11.5	64.7	593.7
Lower	18.2%	4.6	48.6	11.5	64.7	59.4

Source: Deloitte Access Economics analysis.

### Cost-effectiveness of best practice intervention and prevention

The evidence and modelling described in this report demonstrate that EDs have a huge impact on society. However, more can be done to help reduce the burden of EDs. Based on the available literature, a range of effective interventions are available to treat EDs. Another primary focus of this report was to summarize evidence pertaining to the cost-effectiveness of stepped care and integrated care models, which are recognized as best practice in the care of people with EDs.

- **Stepped care** is an evidence-based, staged system comprising a hierarchy of interventions, from the least to the most intensive, meaning that treatment is available to meet an individual's needs at the point in time that they require the treatment.
- **Integrated care** is characterized by the comprehensive delivery of health services, designed according to the multidimensional needs of the population and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care.
- Often, there is little distinction between stepped and integrated care models in the evidence base. However, stepped and integrated care have been separately discussed in this report as they can involve different care settings – for example, stepped care for an individual may include residential care following by an intensive outpatient (IOP) program, while a program delivered solely in an outpatient setting could still be integrated care.

There is limited literature evaluating the cost-effectiveness of the stepped and integrated models of care. Outcomes have been shown to improve with stepped care treatment compared to CBT alone (although it is recognized that CBT is often delivered as a treatment within the context of stepped care), and the time burden upon caregivers diminished substantially. The incremental cost-effectiveness ratio (ICER) was \$12,146 per person who abstained from BN behaviors for stepped care and \$20,317 for CBT, suggesting that stepped care may be superior to single step interventions delivered in isolation.

The integrated care model is likely to provide cost-effective treatment by better offering multiple disciplines (e.g. medicine, nutrition, psychology/social work and psychiatry) to support a patient's individual needs and their symptoms. Partial hospitalization programs (PHPs) may also offer significant cost savings compared to inpatient care. In addition, specialist outpatient care may also be superior compared to inpatient treatment (chapter 6).

There are a range of treatments aimed at reducing the burden of EDs, many of which include a psychological or psychotherapy component. Evidence discussed in the literature focused on the effectiveness of: (1) individual therapy; (2) CBT; (3) FBT; (4) hospitalization; (5) internet-based treatment; (6) physical therapy; (7) pharmaceuticals; and (8) other complementary therapies. Many of these treatment strategies may improve symptoms of ED, although there is mixed or insufficient evidence outlining how these treatments may impact on the social and economic costs of EDs in the US.

In addition to treatment for known cases of EDs, prevention strategies may be put in place to help people at risk of developing an ED. While a review of prevention strategies was not a primary focus of this report, primary prevention strategies seek to reduce the onset and may involve targeting entire populations (universal) or specific population subgroups or high risk groups (targeted). Secondary prevention seeks to reduce duration or severity of EDs. Significant progress has been made in translating ED risk factor research into successful secondary preventive interventions.

### Recommendations for future research

This report makes an important contribution to the body of evidence regarding EDs, demonstrating that EDs also impose substantial costs in men and older populations, not only in younger adults. Further, it shows the range of economic costs beyond the direct costs of treatment, including informal caregivers, productivity and broader costs to society. It also values the reduction in wellbeing that occurs due to EDs. This review of evidence and modelling therefore demonstrates (perhaps for the first time) the diversity of EDs both in terms of affected groups, burden to society, and treatments.

However, there are several areas where future research should be undertaken to assist in the prevention and treatment of EDs. For example, there is insufficient evidence regarding EDs of the aging community and the long-term economic costs. This is especially pertinent given the perceptions between EDs being primarily associated with young people.

Moreover, future research is required to understand whether the cost of ED treatment differs by race/ethnicity, gender identity or other important identity groups marginalized by structural barriers to care, such as by rural residence, disability, or residence in a state without Medicaid expansion. Similarly, further research is required to understand and estimate the additional costs of EDs that may be attributable to structural racism and other structural oppressions in the US.

There is also a need to understand the long-term effects of EDs and the impact of comorbidities on the costs associated with EDs. For example, there is a lack of literature exploring the costs associated with physical and psychological aspects related to EDs. Finally, research is also needed to understand the costs associated with nutritional care for EDs, such as the cost of seeing a dietitian for an ongoing basis.

In part, these gaps in the research may be addressed by improving the quality of data collection, and it is important that nationally representative surveys are enabled to monitor the impact of EDs across the health system, and broader societal costs including productivity and informal care costs.

Another area for future research could be to estimate the costs associated with early intervention or preventable costs of not identifying EDs. For example, social and economic cost savings might be possible through screening, which could identify people with emerging or early EDs in primary healthcare, schools and workplaces who could benefit from early treatment. Screening and early intervention could assist in avoiding the need to access acute care or more structured and intensive care at a later point in time, which would be more costly. Finally, there is also a need to better understand the cost-effectiveness of best practice models of care in the US. New research should continue to focus on the comparative cost-effectiveness of stepped and integrated care.

#### **Deloitte Access Economics**

# 1 Background

## 1.1 Introduction

The Strategic Training Initiative for the Prevention of Eating Disorders, based at the Harvard T.H. Chan School of Public Health and Boston Children’s Hospital, and the Academy for Eating Disorders engaged Deloitte Access Economics to estimate the social and economic impact of EDs in the US.

EDs are a group of illnesses that can impact an individual and their family through complex mental and physical impairments. The main forms of EDs considered for this report included AN, BN, BED, and OSFED. Avoidant restrictive food intake disorder (ARFID), pica, and rumination disorder are also described briefly in the background (section 1.3) although they were excluded from the scope of the report as there are a lack of comprehensive economic data available for these conditions.

EDs are chronic conditions with substantial long-term physical and social sequelae from which recovery can be difficult. They are associated with substantial long-term impacts, including death. Understanding the social and economic costs of these conditions is important to substantiating and guiding additional investment in prevention and treatment strategies for EDs.

The report is structured as follows:

- The rest of chapter 1 provides an overview of the methodology used to estimate the cost of EDs, and provides a high-level overview of EDs, their risk factors, and treatment strategies.
- Chapter 2 provides an estimate of the prevalence of EDs and the excess deaths associated with EDs. This includes a brief summary of available prevalence literature, estimates of one-year and lifetime prevalence, one-year prevalence projections from 2018-19 to 2029-30, and estimated excess deaths associated with EDs. One-year prevalence estimates for 2018-19 were used as a basis for calculating financial costs in chapter 4 and the loss of wellbeing in chapter 5.
- Chapter 3 summarizes several interviews that were conducted to assess the impact of EDs on the individual, their families, and society more broadly.
- Chapter 4 provides estimated financial costs of EDs in 2018-19, including health system costs, productivity costs, informal care costs, and efficiency losses.
- Chapter 5 estimates the reduction in wellbeing due to EDs in 2018-19 using the burden of disease methodology, where lost wellbeing was measured using DALYs.
- Chapter 6 summarizes the available evidence on the effectiveness and benefits of existing treatments for EDs, including stepped-based and integrated treatment compared to treatment as usual or standard care as defined in the literature.
- Finally, chapter 7 summarizes the major findings of this report and recommends a small number of high priority areas of research for the future.

## 1.2 Methodological overview

This section describes the approach taken to estimate the costs of EDs in the US and outlines some of the key economic terms, how costs are borne by members of society, and some of the underlying methodology presented throughout this report. Specific methodologies for each of the costs associated with EDs are outlined further in the chapter where they are discussed.

The costs of EDs in the US were estimated from a societal perspective for the fiscal year between 1 October 2018 and 30 September 2019 (referred to as “2018-19” in this report) using cost-of-illness methods.<sup>6</sup> Costs were estimated using a prevalence approach, where prevalence was

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<sup>6</sup> The financial costs considered here only relate to the 12-month costs of the condition in 2018-19. However, given that many EDs are chronic conditions and last multiple years, it is likely that the actual costs associated with these prevalent cases would be much higher and span across a number of years for some individuals. In addition, EDs may increase the risk of osteoporosis, some cancers, heart damage, digestive dysfunction, poor dental health, among other conditions. While these downstream costs have not been included in this report, they may still be substantial. Further research is required to understand these costs.

estimated based on a combination of nationally representative surveys and modelling studies in the US. A prevalence approach measures the number of people with an ED at a point in time, and estimates the costs incurred due to EDs for a given year (e.g. 2018-19). The costs from remitted cases (i.e. people who have had EDs in the past, but no longer do) are excluded using this approach.

Costs were then primarily generated<sup>7</sup> by multiplying prevalence by mean incremental costs for people with EDs across a range of cost components. The broad types of costs associated with EDs included in this report are:

- **financial costs to the US health system**, which include hospital costs and residential treatment facilities,<sup>8</sup> primary care provider and specialist services including mental health professionals, the cost of pharmaceuticals and of over-the-counter medications, allied health services (in particular mental healthcare providers), and research costs.
- **productivity costs**, which include reduced workforce participation, reduced productivity at work, loss of future earnings due to premature mortality, and the value of informal care (lost productive income of caregivers who provide help to people with EDs).
- **other costs**, which include transfer costs, and their associated efficiency losses, or reduced economic efficiency, associated with the need to levy additional taxation to fund provision of government services.

The value of reduced wellbeing for people with EDs was also estimated. While the loss of wellbeing is not a financial cost, reduced quality of life due to impaired functioning and premature death that result from EDs can be measured in monetary terms by multiplying a VSLY by the years of healthy life lost using the burden of disease methodology.

The costs of EDs are borne by different individuals or sectors of society. Clearly the people living with EDs and their loved ones bear costs, but so do employers, government, co-workers, community groups and other members of society.

It is important to understand how costs are shared in order to make informed decisions regarding interventions. For this analysis, a payer perspective approach was adopted, falling short of delving into second round or longer-term dynamic impacts.

- From the employer's perspective, depending on the impact of EDs, work loss or absenteeism will lead to costs such as higher wages (i.e. accessing skilled replacement short-term labor) or alternatively lost production or other non-wage costs. While these costs may be borne by the employer in part, employers may eventually pass these on to society in the form of higher prices for goods and services.
- Similarly, for the costs associated with the health system and community services provided to the person, although the government pays for a proportion of this cost, taxpayers (society) are the ultimate source of funds.

Typically, six groups bear costs and pay or receive transfer payments, including: (1) people with EDs; (2) friends and family (including caregivers); (3) employers; (4) governments; (5) other payers (e.g. private health insurers); and (6) the rest of society (not-for-profits and other organizations).

### 1.3 Definitions

EDs are a group of mental illnesses that can impact an individual and their loved ones through complex mental and physical impairments. The group includes AN, BN, BED, ARFID, pica, rumination disorder and OSFED. These disorders are defined in the *American Psychiatric Association's Diagnostic and Statistical Manual (DSM-5)* and the diagnostic criteria are briefly

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<sup>7</sup> Some costs were generated using a top-down approach, for example, by utilizing estimates of the total cost of care in hospital, or by modelling the costs of residential care based on the capacity of the system. Specific methodologies for each cost component have been described in more detail throughout the report.

<sup>8</sup> Data were also sought for partial hospitalization and intensive outpatient treatment for EDs, although there were insufficient data to separately discuss these in the report.



summarized in Table 1.1. As noted, only AN, BN, BED and OSFED were considered within the scope of this analysis.<sup>9</sup>

Table 1.1: Overview of the main diagnostic criteria that forms the definition of each ED

ED	Diagnostic criteria
AN	<ul style="list-style-type: none"> <li>• Restriction of energy intake leading to a significantly low body weight and a fear of weight gain</li> <li>• Intense fear of gaining weight or becoming fat, or persistent behavior that interferes with weight gain</li> <li>• Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body shape or weight on self-evaluation, or shape is experienced, undue influence of body shape or weight on self-evaluation or persistent lack of recognition of the seriousness of current low body weight</li> </ul>
BN	<ul style="list-style-type: none"> <li>• Recurrent episodes of binge-eating and compensatory behavior (purging) to prevent weight gain</li> <li>• Recurrent inappropriate compensatory behavior to prevent weight gain</li> <li>• The binge-eating and inappropriate behavior both occur, on average, at least once a week for three months</li> <li>• The disturbance does not occur exclusively during episodes of AN</li> </ul>
BED	<ul style="list-style-type: none"> <li>• Recurrent episodes of binge-eating and these episodes are not associated with a concurrent diagnosis of AN or BN</li> <li>• Marked distress regarding binge-eating is present</li> <li>• The binge-eating occurs, on average, at least once a week for three weeks</li> </ul>
ARFID	<ul style="list-style-type: none"> <li>• An eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs.</li> <li>• Eating behavior is not explained by lack of available food or cultural practices</li> <li>• The ED is not attributable to another medical condition</li> </ul>
Pica	<ul style="list-style-type: none"> <li>• Persistent eating of non-nutritive, non-food substances over a period of at least 1 month</li> <li>• Eating behavior is not part of culturally supported or socially normative practice</li> </ul>
Rumination disorder	<ul style="list-style-type: none"> <li>• Repeated regurgitation of food over a period of at least 1 month</li> <li>• Repeated regurgitation is not due to another medical condition – mental or physical</li> </ul>
OSFED	<ul style="list-style-type: none"> <li>• A clinically significant disturbance of eating behavior the symptoms of which do not fulfill the criteria for other EDs</li> </ul>

Source: American Psychiatric Association (2013).

The DSM-5 separates the symptom, causes and physical behaviors into meaningful sub-groupings using a hierarchical approach. This involves classifying mental illnesses over the whole spectrum (AN patients restrict energy intake) and then specifying dimensions within the mental disorder (AN patients have thoughts related to body dysphoria). This approach recognizes that symptoms lie on a spectrum between patients that experience the same ED rather than providing specific markers of severity that the patient must meet to be diagnosed. In 2013, the DSM-5 formally recognized BED and ARFID as diagnosable conditions, while OSFED was defined as a sub-clinical manifestation of other symptoms that do not satisfy the diagnosis criteria for other EDs.<sup>10</sup>

<sup>9</sup> It is noted that ARFID, pica and rumination disorder were excluded from the scope of the analysis due to expected data limitations before commencing the research project.

<sup>10</sup> American Psychiatric Association, Diagnostic and statistical manual of mental disorders (5th Ed, 2013). <<https://doi.org/10.1176/appi.books.9780890425596>>.

#### 1.4 Etiology and risk factors

EDs develop from a complex interaction of psychological risk factors, sociocultural influences, and biological and genetic predispositions.<sup>11, 12, 13</sup>

Recent research has highlighted that there is a substantial role for genetics in eating disorder etiology through familial aggregation of EDs, twin-based heritability estimates of EDs, and genome-wide association studies.<sup>14, 15, 16, 17</sup>

Some risk factors for EDs have been shown to be common, meaning they are applicable to all EDs, or even to other mental health disorders. Common risk factors include gender, ethnicity, early childhood eating and gastrointestinal problems, negative self-evaluation, sexual abuse and other adverse experiences.<sup>18, 19</sup> Research has also indicated that anxiety disorder (especially social anxiety) can precede the onset of an eating disorder.<sup>20, 21</sup>

Female gender is clearly elevated in the development of AN and BN, and somewhat elevated in BED; the role of gender is unclear in ARFID.<sup>22</sup>

Further, EDs may also be more common among athletes who compete in sports that emphasize leanness, lower weight aesthetics or weight requirements for competition.<sup>23</sup>

Specific risk factors are those that have been found to be applicable only to a particular eating disorder. Examples of specific risk factors include elevated weight and shape concerns and dietary restraint, such as the use of diet pills and laxatives, which may lead to increased risk of developing an ED. Recent research has also indicated that parental redeployment in military families is associated with more frequent adolescent shape and weight concerns.<sup>24</sup>

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<sup>11</sup> Mayhew, A.J., Pigeyre, M., Couturier, J. and Meyre, D., (2018). An evolutionary genetic perspective of eating disorders. *Neuroendocrinology*, 106(3), pp.292-306.

<sup>12</sup> Striegel-Moore, R.H. and Bulik, C.M., (2007). Risk factors for eating disorders. *American psychologist*, 62(3), p.181.

<sup>13</sup> Mazzeo, S.E., Mitchell, K.S., Bulik, C.M., Reichborn-Kjennerud, T., Kendler, K.S. and Neale, M.C., (2009). Assessing the heritability of anorexia nervosa symptoms using a marginal maximal likelihood approach. *Psychological medicine*, 39(3), pp.463-473.

<sup>14</sup> Hübel, C., Leppä, V., Breen, G. and Bulik, C.M., (2018). Rigor and reproducibility in genetic research on eating disorders. *International Journal of Eating Disorders*, 51(7), pp.593-607.

<sup>15</sup> Polderman, T.J., Benyamin, B., De Leeuw, C.A., Sullivan, P.F., Van Bochoven, A., Visscher, P.M. and Posthuma, D., (2015). Meta-analysis of the heritability of human traits based on fifty years of twin studies. *Nature genetics*, 47(7), p.702.

<sup>16</sup> Duncan, L., Yilmaz, Z., Gaspar, H., Walters, R., Goldstein, J., Anttila, V., Bulik-Sullivan, B., Ripke, S., Eating Disorders Working Group of the Psychiatric Genomics Consortium, Thornton, L. and Hinney, A., (2017). Significant locus and metabolic genetic correlations revealed in genome-wide association study of anorexia nervosa. *American journal of psychiatry*, 174(9), pp.850-858.

<sup>17</sup> Pettersson, E., Lichtenstein, P., Larsson, H., Song, J., Agrawal, A., Børglum, A.D., Bulik, C.M., Daly, M.J., Davis, L.K., Demontis, D. and Edenberg, H.J., (2019). Genetic influences on eight psychiatric disorders based on family data of 4 408 646 full and half-siblings, and genetic data of 333 748 cases and controls. *Psychological medicine*, 49(7), pp.1166-1173.

<sup>18</sup> Jacobi, C., Hayward, C., de Zwaan, M., Kraemer, H. C., & Agras, W. S. (2004). Coming to terms with risk factors for eating disorders: application of risk terminology and suggestions for a general taxonomy. *Psychol Bull*, 130(1), 19-65.

<sup>19</sup> Culbert, K. M., Racine, S. E., & Klump, K. L. (2015). Research Review: What we have learned about the causes of eating disorders - a synthesis of sociocultural, psychological, and biological research. *J Child Psychol Psychiatry*, 56(11), 1141-1164.

<sup>20</sup> Bulik, C.M., (2002). Anxiety, depression and eating disorders. *Eating disorders and obesity: A comprehensive handbook*, 2(1), pp.193-198.

<sup>21</sup> Swinbourne, J.M. and Touyz, S.W., (2007). The co-morbidity of eating disorders and anxiety disorders: A review. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, 15(4), pp.253-274.

<sup>22</sup> Weissman, R. S. (2019). The Role of Sociocultural Factors in the Etiology of Eating Disorders. *Psychiatr Clin North Am*, 42(1), 121-144. doi:10.1016/j.psc.2018.10.009

<sup>23</sup> Kong, P., & Harris, L. M. (2015). The sporting body: body image and eating disorder symptomatology among female athletes from leanness focused and nonleanness focused sports. *The Journal of psychology*, 149(2), 141-160.

<sup>24</sup> Neyland H, et al, (2020). Parental deployment and distress, and adolescent disordered eating in prevention-seeking military dependents. *International Journal of Eating Disorders*, vol 53, no. 2, pp.201-209.

## 1.5 Treatment

Treatment for EDs may be delivered by various health professionals, in multidisciplinary teams, including family medicine physicians, psychologists, social workers, pediatricians, psychiatrists, dietitians and others. Treatment can be delivered across one or more settings (e.g. inpatient and outpatient facilities, day programs or community-based healthcare settings), although more intensive care (inpatient medical, psychiatric care or residential treatment) is only required in severe cases.

Practice guidelines developed by the American Psychiatric Association suggest that people with EDs should be offered a continuum of care, such as stepped care, that is appropriately tailored to their needs at any time in their treatment.<sup>25</sup> Stepped care allows patients to “step-up” or “step-down” the intensity of their treatment by providing a hierarchy of available interventions, from least to most intensive, which can be matched to the individual’s needs. This care should be delivered in an integrated way, involving a multidisciplinary team of providers working across settings and levels of care. A number of specific treatments may be offered, including family-based treatment, CBT, nutritional services and interpersonal psychotherapy, among others. Low levels of care, such as self-help or guided self-help may also be recommended.

Pharmacotherapy can also be administered for the treatment of EDs. For example, antidepressants have been shown to be moderately effective for the treatment of BN<sup>26</sup>; several large studies have shown clear evidence of impact for the use of lisdexamfetamine in treating BED<sup>27</sup>; while research has indicated that antipsychotics are not effective in treating AN.<sup>28</sup>

In addition to treatment for known cases of EDs, prevention strategies may be put in place to help people at risk of developing an ED. Primary prevention strategies seek to reduce the onset, duration and severity of symptoms that translate into clinical presentation of an ED. Such strategies target the whole community, particularly high-risk groups of individuals. Secondary prevention strategies, such as screening, can be used to identify and support people close to illness onset in order to engage them in care at a point when treatment may be most effective.

As noted, Chapter 6 summarizes the available evidence on the effectiveness and benefits of existing treatments for EDs, including stepped-based and integrated treatment compared to treatment as usual or standard care as defined in the literature.

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<sup>25</sup> American Psychiatric Association, (2012). Guideline watch (August 2012): Practice guideline for the treatment of patients with eating disorders.

<sup>26</sup> McElroy, S.L., Guerdjikova, A.I., Mori, N. and Romo-Nava, F., (2019). Progress in developing pharmacologic agents to treat bulimia nervosa. *CNS drugs*, 33(1), pp.31-46.

<sup>27</sup> Crow, S.J., (2019). Pharmacologic Treatment of Eating Disorders. *The Psychiatric clinics of North America*, 42(2), pp.253-262.

<sup>28</sup> de Vos, J., Houtzager, L., Katsaragaki, G., van de Berg, E., Cuijpers, P., & Dekker, J. (2014). Meta analysis on the efficacy of pharmacotherapy versus placebo on anorexia nervosa. *J Eat Disord*, 2(1), 27. doi:10.1186/s40337-014-0027-x

## 2 Prevalence

This chapter describes the approach used to estimate the prevalence and mortality of EDs by type of ED – AN, BN, BED and OSFED – age and gender in the US in 2018-19. Estimates are provided of one-year prevalence in 2018-19, lifetime prevalence (defined as the estimated number of people alive today who have experienced an ED in their lifetime to date), and one-year prevalence projections from 2018-19 to 2029-30. The number of excess deaths associated with EDs are also estimated.

### Key findings

- Of people currently living in the United States, it was estimated that 6.0% of females (14.4 million people) and 4.07% of males (6.6 million people) had experienced an ED at some stage of their lifetime to date.
- The overall one-year prevalence was estimated to be 1.66%, representing 5.48 million people in the US in 2018-19. Estimates were higher in females (2.62%), compared with males (0.67%). The most common ED was OSFED, with prevalence of 1.18% for females and 0.27% for males.
- Assuming no change in prevalence, demographic trends suggest that the number of ED cases will increase from 5.48 million individuals in 2018-19 to 5.75 million people in 2029-30.
- Overall, 10,200 deaths in the US were associated with EDs in 2018-19 (with estimates ranging from 5,500 to 22,000). An increased mortality rate was applied only to people aged between 15 and 64 years, which may be expanded if there is further research available that will allow for age specific relative risks to be used in the modelling.

### 2.1 Overview of prevalence literature

To inform the prevalence of EDs in the US for 2018-19, a literature review<sup>29</sup> was conducted to identify nationally representative prevalence sources (search strings provided in A.2). The most relevant prevalence sources for this study are summarized briefly in Table 2.1.

The systematic review by Galmiche et al. (2019) is the most comprehensive and recent review of ED prevalence to date. The authors applied exclusion criteria including articles that did not relate to a population with EDs, where prevalence data were not available or diagnoses were inaccurate, where the study did not relate to the general population, where the full text was not available or published in a language other than English. After these criteria were applied, Galmiche et al. (2019) included 94 studies with a specific ED diagnosis in their systematic review,<sup>30</sup> with reported overall prevalence of EDs ranging between from 2.0% to 13.5%.<sup>31</sup> The results showed that prevalence has been increasing over time, based on publication date, and also that the prevalence by condition can vary widely across population groups (e.g. Asia compared to Europe or America).

<sup>29</sup> This used targeted search strings in PubMed as well as desktop research for government publications and literature available from Google Scholar. An overview of generic search strings used is provided in Appendix A.

<sup>30</sup> There were 27 additional studies with a broad ED diagnosis (i.e. the type of ED was not further specified or the study did not provide DSM or ICD based diagnoses).

<sup>31</sup> Galmiche, M., Déchelotte, P., Lambert, G., & Tavalacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: a systematic literature review. *The American Journal of Clinical Nutrition*, 109(5), 1402–1413.

Table 2.1: Summary of prevalence estimates of EDs

Study	Brief details	One-year prevalence	Lifetime prevalence
Duncan et al. (2017) <sup>32</sup>	Examined prevalence based on data from the Collaborative Psychological Epidemiological Surveys (CPES), a nationally representative survey of 12,337 US adults.	AN: 0.0% BN: 0.4% BED: 1.1%	AN: 0.4% BN: 1.1% BED: 2.3%
Galmiche et al. (2019) <sup>33</sup>	International systematic review based on 94 included studies that reported DSM or ICD based prevalence estimates.	AN: 0.07% BN: 0.55% BED: 1.01%	AN: 0.81% BN: 1.26% BED: 1.91% OSFED: 3.96%
Glazer et al. (2019) <sup>34</sup>	Prospective assessments for EDs based on a cohort of 9,031 US females aged between 9 and 15 years old.	AN: 0.33% BN: 0.13% BED: 1.00%	Not reported
Hudson et al. (2007) <sup>35</sup>	Prevalence results from NCS-R, a survey of US adults from 2001 to 2003.	AN: No cases BN: 0.3% BED: 1.2%	AN: 0.6% BN: 1.0% BED: 2.8%
Rozzell et al. (2019) <sup>36</sup>	Survey results from the nationally representative 2016 and 2017 Adolescent Brain Cognitive Development Survey which used a sample of 4,524 children aged 9 to 10 years old.	AN: 0.10% BN: No cases BED: 0.60% OSFED: 0.70%	Not reported
Swanson et al. (2011) <sup>37</sup>	Analyzed results from NCS-A, a survey of US adolescents (13 to 18 years old) from 2001 to 2004.	AN: 0.2% BN: 0.6% BED: 0.9%	AN: 0.3% BN: 0.9% BED: 1.6%
Udo and Grilo (2018) <sup>38</sup>	Prevalence estimates based on recoded data from NESARC-III, a survey of adults from 2012 to 2013.	AN: 0.05% BN: 0.14% BED: 0.44%	AN: 0.80% BN: 0.28% BED: 0.44%
Ward et al. (2019) <sup>39</sup>	Markov process to model prevalence for those aged 39 years old and younger. Estimates were fit to prior assumptions based on data from Swanson et al. (2011), Hudson et al. (2007) and other studies.	AN: 0.18% BN: 0.25% BED: 0.72% OSFED: 3.13%	AN: 0.50% BN: 0.78% BED: 1.81% OSFED: 8.21%

Source: as noted.

It is also worth noting that there have been advances in the diagnosis and classification of EDs in both the DSM and International Classification of Diseases (ICD) classifications of EDs. The diagnostic criteria for AN and BN are now less restrictive, meaning that more people can be

<sup>32</sup> Duncan, A. E., Ziobrowski, H. N., & Nicol, G. (2017). The prevalence of past 12-month and lifetime DSM-IV eating disorders by BMI category in US men and women. *European Eating Disorders Review*, 25(3), 165-171.

<sup>33</sup> Galmiche, M., Déchelotte, P., Lambert, G., & Tavolacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: a systematic literature review. *The American journal of clinical nutrition*, 109(5), 1402–1413.

<sup>34</sup> Glazer, K. B., Sonnevile, K. R., Micali, N., Swanson, S. A., Crosby, R., Horton, N. J., ... & Field, A. E. (2019). The course of eating disorders involving bingeing and purging Among adolescent girls: prevalence, stability, and transitions. *Journal of Adolescent Health*, 64(2), 165-171.

<sup>35</sup> Hudson, J. I., Hiripi, E., Pope Jr, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological psychiatry*, 61(3), 348-358.

<sup>36</sup> Rozzell, K., Moon, D. Y., Klimek, P., Brown, T., & Blashill, A. J. (2019). Prevalence of eating disorders among us children aged 9 to 10 years: data from the Adolescent Brain Cognitive Development (ABCD) study. *JAMA pediatrics*, 173(1), 100-101.

<sup>37</sup> Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents: Results from the national comorbidity survey replication adolescent supplement. *Archives of general psychiatry*, 68(7), 714-723.

<sup>38</sup> Udo, T., & Grilo, C. M. (2018). Prevalence and correlates of DSM-5–defined eating disorders in a nationally representative sample of US adults. *Biological psychiatry*, 84(5), 345-354.

<sup>39</sup> Ward, Z. J., Rodriguez, P., Wright, D. R., Austin, S. B., & Long, M. W. (2019). Estimation of Eating Disorders Prevalence by Age and Associations With Mortality in a Simulated Nationally Representative US Cohort. *JAMA network open*, 2(10), e1912925-e1912925.

diagnosed with a distinct eating disorder diagnosis now, rather than be classified in a “catch-all” “other eating disorder” category as was common in previous versions of the DSM and ICD classifications. Academic studies show mixed impacts of the change in diagnostic classification on the overall prevalence of EDs, but clear changes in the case mix with increased prevalence of AN, BN, and BED compared with the change from EDNOS to OSFED.<sup>40</sup> While these changes are important, very few studies and data sources allow an assessment of the cost impacts of EDs under DSM-5 or ICD-11 criteria, so the evidence in this report largely draws on the previous definitions of EDs (including for prevalence).

Given that prevalence is used as an input to estimate the costs of EDs in our study, a stronger focus was placed on studies that provide prevalence by age and gender. The major reason disaggregated estimates were sought was because a human capital approach was used to estimate the costs of EDs and productivity, and earnings vary widely across age and gender groups. As such, it was not possible to base the analysis directly on the aggregated estimates provided by Galmiche et al. (2019).

There are a range of survey and other data sources within the US that can be used to estimate the prevalence of EDs, including by age and gender. The most nationally representative population-based sources for estimating the prevalence of EDs in adults include the National Comorbidity Survey Family (NCS-A and NCS-R), and the National Epidemiological Survey on Alcohol and Related Conditions-III (NESARC-III). Both surveys include questions on EDs relating to the DSM criteria for diagnosing EDs, rather than simply asking individuals to self-report whether they have ever had an ED (e.g. the National Health and Wellness Survey) or relying on diagnosed cases (e.g. the Medical Expenditure Panel Survey, or MEPS).<sup>41</sup>

Ward et al. (2019) was the only study found that provided age and gender stratified prevalence by type of ED, although estimates were available only for those aged 39 years and younger. While Ward et al. (2019) is a modelling study, it does rely on and calibrate results to one of the most representative studies in the US for those aged 13 years to 39 years old (the NCS-A and NCS-R and Hudson et al., 2007). **Consequently, one-year and lifetime prevalence estimates of AN, BN, and BED for those aged between 13 and 39 years of age were based on Ward et al. (2019)<sup>42</sup>.**

The one-year prevalence of EDs among those aged older than 39 years old was based on Udo and Grilo (2018)<sup>43</sup> who conducted an analysis of the NESARC-III survey based on a nationally representative sample of 36,309 adults. The authors published estimated prevalence rates for AN, BN, and BED disaggregated by age and gender.

The lifetime prevalence reported in Ward et al. (2019) at 39 years of age are quite comparable to the rates reported by Galmiche et al. (2019). So, lifetime prevalence in people aged 40 years or older were modelled based on incidence and lifetime prevalence estimates published by Ward et al. (2019). The specific methods to estimate lifetime rates are discussed further in section 2.3.

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<sup>40</sup> For example, Dahlgren et al. (2017) includes a discussion of the changes, noting that the prevalence of other EDs has decreased as an expected change of the diagnostic criteria (i.e. more people now meet the criteria for AN, BN and BED compared to rates reported under DSM-IV).

Dahlgren, C. L., Wisting, L., & Rø, Ø. (2017). Feeding and eating disorders in the DSM-5 era: a systematic review of prevalence in non-clinical male and female samples. *Journal of eating disorders*, 5(1), 56.

<sup>41</sup> Evidence was also considered from: the National Health and Wellness Survey, the Collaborative Psychological and Epidemiological Surveys, the National Survey of American Life, the National Growth and Health Study, the National Latino and Asian American Study, Add Health, the National Health Interview Survey, the MEPS, and Census data, among others. Some studies were excluded as they were not nationally representative while others were excluded as they did not use DSM criteria to estimate prevalence.

<sup>42</sup> Ward, Z. J., Rodriguez, P., Wright, D. R., Austin, S. B., & Long, M. W. (2019). Estimation of Eating Disorders Prevalence by Age and Associations With Mortality in a Simulated Nationally Representative US Cohort. *JAMA network open*, 2(10), e1912925-e1912925.

<sup>43</sup> Udo, T., & Grilo, C. M. (2018). Prevalence and correlates of DSM-5–defined eating disorders in a nationally representative sample of US adults. *Biological psychiatry*, 84(5), 345-354.

In general, almost all of the considered sources do not capture or report prevalence for children. These surveys also provide limited data in older age groups, where estimated rates are often zero for certain age groups due to sampling variability.

For younger age groups, the best available sources included:

- Glazer et al. (2019)<sup>44</sup> conducted prospective assessments for EDs based on a cohort of 9,031 US girls aged between 9 and 15 years old. The authors reported age stratified prevalence for AN, BN, and BED. Glazer et al. (2019) found prevalence for those aged 9 to 12 years of age of 0.14% for AN, 0.01% for BN, 0.44% for BED, and 2.04% for OSFED.
- Rozzell et al. (2019)<sup>45</sup> also provided a prevalence estimate of EDs among the US population aged from 9 to 10 years old. To calculate prevalence, the authors analyzed survey results from the nationally representative Adolescent Brain Cognitive Development Survey, which used a sample of 4,524 children. The study reported prevalence of 0.1% for AN, 0.0% for BN<sup>46</sup>, 0.6% for BED, 0.7% for OSFED, and an overall rate of EDs of 1.4%.

**The prevalence of EDs across females aged between 9 to 12 years of age was assumed to be an arithmetic average of the rates published by Glazer et al. (2019) and Rozzell et al. (2019). The estimated prevalence of EDs among boys in these age groups was based on the rates published by Rozzell et al. (2019).** These studies were used as the basis for both one-year and lifetime prevalence in these ages, conservatively assuming that prevalence before 9 years is zero.<sup>47</sup>

In the absence of a nationally representative source across all ages, the **prevalence of OSFED was calculated by estimating the proportion of OSFED to all other EDs based on studies included in a large systematic review published by Galmiche et al. (2019).** Based on this approach, it was estimated that **OSFED represented 39.5% of ED cases among males, and 44.2% of cases among females in the US in 2018-19 (Table 2.2).** The underlying data were based on a subset of all studies where studies were selected provided that they included prevalence estimates for all four EDs (AN, BN, BED, and OSFED or EDNOS), and that they were conducted in high-income countries.

Further adjustment was applied to these prevalence estimates (both one-year and lifetime) to exclude any potential double counting of prevalent cases.<sup>48</sup> The prevalence estimates by condition, age and gender were divided by the average number of EDs among an individual who had at least one ED. Based on the underlying results published in the NCS-R, it was estimated that **each person with an ED in the year has on average 1.13 different EDs over the period** (Alegria et al., 2016).<sup>49</sup>

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<sup>44</sup> Glazer, K. B., Sonnevile, K. R., Micali, N., Swanson, S. A., Crosby, R., Horton, N. J., ... & Field, A. E. (2019). The course of eating disorders involving bingeing and purging among adolescent girls: prevalence, stability, and transitions. *Journal of Adolescent Health, 64*(2), 165-171.

<sup>45</sup> Rozzell, K., Moon, D. Y., Klimek, P., Brown, T., & Blashill, A. J. (2019). Prevalence of eating disorders among us children aged 9 to 10 years: data from the Adolescent Brain Cognitive Development (ABCD) study. *JAMA pediatrics, 173*(1), 100-101.

<sup>46</sup> There were no observed cases of BN.

<sup>47</sup> Ward et al. (2019) and Hay et al. (2015) report positive prevalence among children aged less than nine years old, although these rates are small and within statistical error.

<sup>48</sup> While the DSM-5 generally defines most ED conditions hierarchically, for example an individual can have Atypical AN as part of OSFED if they do not meet all of the requirements for AN, it is possible that an individual may experience different EDs over a given time period (for example, an individual could be diagnosed with OSFED, be treated, and then later in the year have symptoms that match AN or another type of ED). These could be counted as two separate cases, despite the conditions being experienced for the same individual. This report estimates the number of individuals who experience at least one ED in a given year, and it is important that this figure is adjusted to remove any potential double counting.

<sup>49</sup> Comorbidity patterns were separately considered for age and gender groups in the modelling. Data from Alegria et al. (2016). Collaborative Psychiatric Epidemiology Surveys (CPES), 2001-2003 [United States] (ICPSR 20240). Available at: <<https://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240>>.

Table 2.2: Prevalence studies used to inform the share of OSFED compared to all EDs

First author	Country	Prevalence measure	Sample size	OSFED %, men	OSFED %, women	All EDs %, men	All EDs %, women
Ghaderi	Sweden	Point	826	-	0.5%	-	3.1%
Kjelsas	Norway	Point	1,960	1.7%	6.5%	2.5%	8.0%
Flament	Canada	Point	3,043	3.4%	3.4%	7.4%	7.4%
Hay	Australia	Point	6,041	1.4%	1.4%	4.6%	4.6%
Solmi	UK	Point	1,698	2.4%	2.4%	4.4%	4.4%
Micali	UK	12 month	5,542	0.3%	0.3%	3.6%	3.6%
Ernst	Germany	Point	1,654	2.9%	2.9%	-	-
<b>Weighted prevalence</b>				<b>1.6%</b>	<b>2.0%</b>	<b>4.0%</b>	<b>4.6%</b>
<b>OSFED as a proportion of all EDs</b>				<b>39.5%</b>	<b>44.2%</b>		

Source: Adapted based on Galmiche et al. (2019).

## 2.2 One-year prevalence estimates

The overall one-year prevalence of EDs was estimated to be 1.66% in the US in 2018-19. Prevalence was estimated to be higher in females (2.62%) compared to males (0.67%). The most common ED was OSFED with a prevalence of 1.18% for females and 0.27% for males (Table 2.3). Prevalence was highest among the 20-29 year old age group for males and females.

The age and gender stratified prevalence were then multiplied by their respective groups in the current US population, which was estimated to be 330.3 million people in 2018-19<sup>50</sup>, to estimate the number of people with EDs by age and gender in 2018-19. It was estimated that there were 5.5 million people with an ED in the US in 2018-19, comprising 4.4 million females and 1.1 million males (Table 2.4).

<sup>50</sup> United States Census Bureau. (2018). National Population Projections 2017. Retrieved from <<https://www.census.gov/data/datasets/2017/demo/popproj/2017-popproj.html>>.



Table 2.3: One-year prevalence (%) by condition, gender and age, 2018-19

Gender / age (years)	Prevalence (%)				Total
	AN	BN	BED	OSFED	
<b>Male</b>					
0-9	0.02	0.00	0.07	0.07	0.16
10-19	0.15	0.06	0.48	0.48	1.17
20-29	0.23	0.12	0.36	0.46	1.17
30-39	0.17	0.09	0.17	0.28	0.70
40-49	0.02	0.06	0.23	0.20	0.51
50-59	0.01	0.06	0.23	0.20	0.51
60-69	0.02	0.01	0.26	0.19	0.48
70-79	0.02	0.01	0.27	0.20	0.49
80+	0.02	0.01	0.32	0.23	0.58
<b>Total male</b>	<b>0.09</b>	<b>0.05</b>	<b>0.26</b>	<b>0.27</b>	<b>0.67</b>
<b>Female</b>					
0-9	0.01	0.00	0.05	0.13	0.19
10-19	0.19	0.48	1.08	1.65	3.40
20-29	0.41	0.73	2.09	2.56	5.79
30-39	0.30	0.39	1.54	1.77	4.00
40-49	0.10	0.39	0.69	0.94	2.12
50-59	0.07	0.39	0.68	0.90	2.03
60-69	0.10	0.05	0.72	0.69	1.55
70-79	0.09	0.05	0.69	0.66	1.50
80+	0.08	0.04	0.62	0.59	1.33
<b>Total female</b>	<b>0.16</b>	<b>0.32</b>	<b>0.96</b>	<b>1.18</b>	<b>2.62</b>
<b>Total persons</b>	<b>0.12</b>	<b>0.19</b>	<b>0.62</b>	<b>0.73</b>	<b>1.66</b>

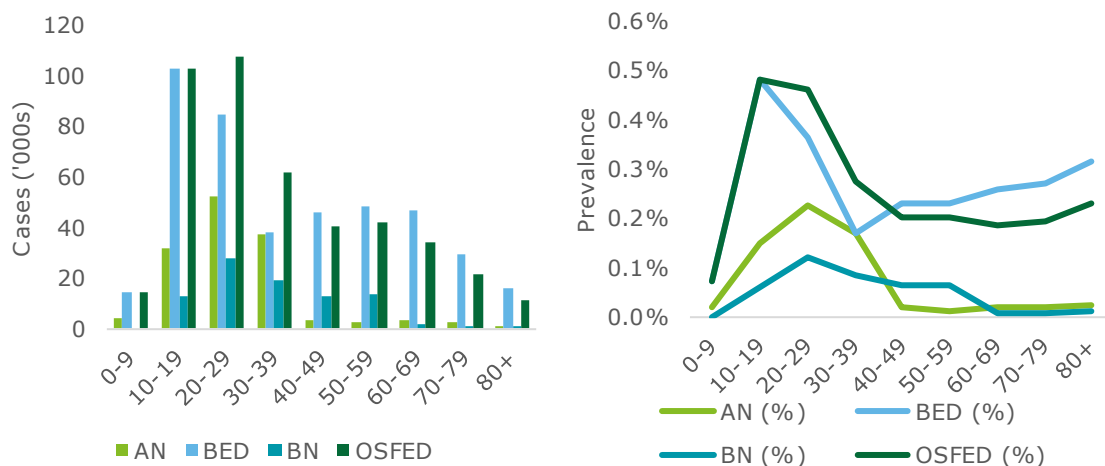
Source: Deloitte Access Economics calculations based on Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019), Udo and Grilo (2018), United States Census Bureau (2018). Note: components may not sum to totals due to rounding.

Table 2.4: One-year prevalent cases: number of affected individuals ('000s), by condition, gender and age, 2018-19

Gender / age (years)	Prevalence ('000s)				Total
	AN	BN	BED	OSFED	
<b>Male</b>					
0-9	4.1	0.0	14.5	14.5	33.2
10-19	32.0	12.5	102.9	103.3	250.7
20-29	52.5	28.2	84.7	107.9	273.4
30-39	37.7	19.1	37.8	61.7	156.4
40-49	3.7	12.7	46.0	40.7	103.2
50-59	2.6	13.3	48.4	42.0	106.3
60-69	3.5	1.6	47.2	34.1	86.5
70-79	2.2	1.0	29.3	21.2	53.7
80+	1.2	0.5	16.0	11.5	29.2
<b>Total male</b>	<b>139.6</b>	<b>89.0</b>	<b>426.8</b>	<b>437.1</b>	<b>1,092.5</b>
<b>Female</b>					
0-9	1.4	0.1	9.4	26.2	37.2
10-19	38.3	98.6	222.6	339.0	698.5
20-29	90.2	163.1	466.1	570.3	1,289.8
30-39	65.5	86.7	338.6	389.0	879.7
40-49	20.5	80.4	140.3	191.2	432.4
50-59	14.4	84.5	147.4	195.3	441.7
60-69	19.4	9.9	144.0	137.4	310.8
70-79	12.1	6.2	89.5	85.4	193.1
80+	6.6	3.3	48.6	46.4	105.0
<b>Total female</b>	<b>268.4</b>	<b>532.9</b>	<b>1,606.5</b>	<b>1,980.3</b>	<b>4,388.1</b>
<b>Total persons</b>	<b>408.0</b>	<b>621.9</b>	<b>2,033.3</b>	<b>2,417.4</b>	<b>5,480.6</b>

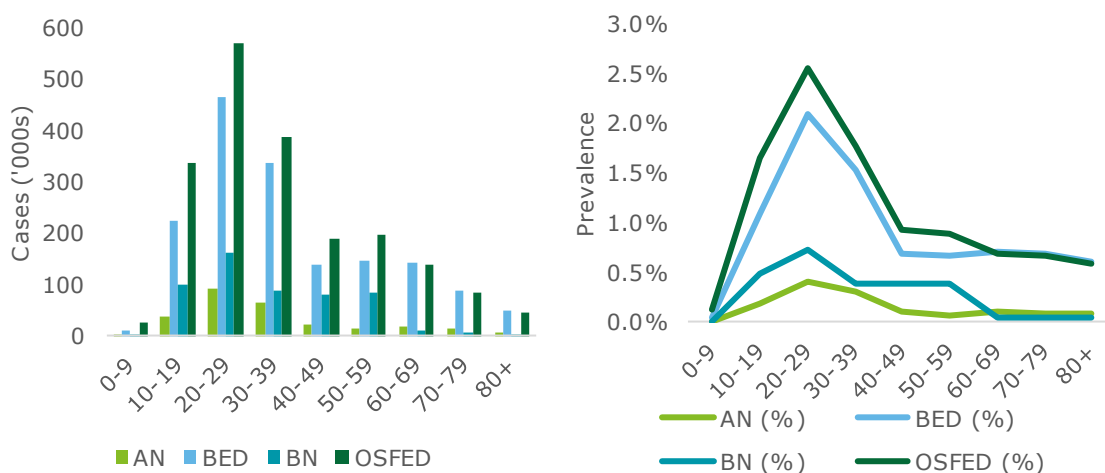
Source: Deloitte Access Economics calculations based on Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019), Udo and Grilo (2018), United States Census Bureau (2018). Note: components may not sum to totals due to rounding.

Chart 2.1: One-year prevalence of EDs among males, by age (in years) and condition, 2018-19



Source: Deloitte Access Economics calculations based on Udo and Grilo (2018), Galmiche et al. (2019), Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019).

Chart 2.2: One-year prevalence of EDs among females, by age (in years) and condition, 2018-19



Source: Deloitte Access Economics calculations based on Udo and Grilo (2018), Galmiche et al. (2019), Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019).

The estimated prevalence in this report is likely to be conservative, with higher rates reported by a range of studies. For example, one-year prevalence estimates reported by Hudson et al. (2007) are higher among adults for BN (0.1% for males, 0.5% for females) and BED (0.8% for males, 1.6% for females). Similarly, Galmiche et al. (2019) found an average one-year prevalence of 0.7% for males and 2.2% for females.

In comparison, the Global Burden of Disease Study (GBD)<sup>51</sup> estimated one-year prevalence to be 0.07% for AN, 0.55% for BN and 0.67% for other EDs (shown as OSFED in Table 2.5). Overall, the GBD estimated there were 1.4 million people with an ED in the US in 2017, with prevalence restricted to people aged 50 years or younger.

Table 2.5 provides a comparison between the estimated prevalence across selected studies.

<sup>51</sup> Institute for Health Metrics and Evaluation (IMHE). (2017). Global Burden of Disease Study. Retrieved from <<http://ghdx.healthdata.org/gbd-results-tool>>.

Table 2.5: Comparison with other published one-year prevalence estimates

Study	AN (%)	BN (%)	BED (%)	OSFED (%)
Hudson et al. (2007)	Not provided	0.30 (SE 0.10)	1.20 (SE 0.20)	Not provided
Udo and Grilo (2018)	0.05 (SE 0.02)	0.14 (SE 0.02)	0.44 (SE 0.04)	Not provided
Institute for Health Metrics and Evaluation (2017)	0.17	0.51	Not provided	0.67*
Galmiche et al. (2019) <sup>52</sup>	0.07	0.55	0.99	Not provided
Deloitte Access Economics estimates	0.12	0.19	0.62	0.73

Source: Deloitte Access Economics analysis based on Hudson et al. (2007), Institute for Health Metrics and Evaluation (2017), Galmiche et al. (2017). \* Institute for Health Metrics and Evaluation represents other EDs not captured by AN or BN: the rate for OSFED (0.73%) was estimated based on the available data by subtracting prevalence of AN and BN from the total prevalence of all EDs, so it may capture cases that would be classified as BED.

### 2.3 Lifetime prevalence

As noted, lifetime prevalence estimates were largely based on Ward et al. (2019), adjusting for OSFED as was done for one-year prevalence (section 2.1)<sup>53</sup>. Academic literature provides limited evidence of incident cases of EDs for those aged 40 years and older.<sup>54</sup> Due to this lack of available data, incidence rates published by Ward et al. (2019) at 39 years of age were applied to lifetime prevalence at 39 years of age and the estimated lifetime prevalence among older age groups in order to derive lifetime prevalence.

The overall lifetime prevalence of EDs was estimated to be 8.60% among females and 4.07% among males (Table 2.6). As with one-year prevalence, OSFED is the most common ED experienced over an individual's lifetime with respective prevalence of 3.82% among females and 1.61% among males. Overall, it was estimated that 21.0 million people in 2018-19 have been impacted by an ED at some point in their lives up to that point, of which 14.4 million cases occurred in women and 6.6 million cases occurred in men (Table 2.7).

<sup>52</sup> Galmiche et al. (2019) reported one-year AN prevalence of 0.05% (0-0.8%) for women and 0.1% (0-0.2%) for men; BN prevalence of 0.7% (0.3-2.2%) for women and 0.4% (0-1.1%) for men; BED prevalence of 1.4% (0.5-3%) for women and 0.6% (0-1.2%) for men.

<sup>53</sup> Lifetime prevalence estimates presented in this section are not forward-looking, i.e. they provide an estimate of individuals alive in the US today who would have experienced an ED in their lifetime to date. These lifetime estimates do not flow into the estimated cost calculations presented in subsequent chapters of this report.

<sup>54</sup> Bueno, B., Krug, I., Bulik, C. M., Jiménez-Murcia, S., Granero, R., Thornton, L., ... & Fernández-Aranda, F. (2014). Late onset eating disorders in Spain: Clinical characteristics and therapeutic implications. *Journal of clinical psychology*, 70(1), 1-17.

Table 2.6: Lifetime prevalence (%), by condition, gender and age, 2018-19

Gender / age (years)	AN	BN	BED	OSFED	Total
<b>Male</b>					
0-9	0.02	0.00	0.07	0.07	0.16
10-19	0.19	0.08	0.69	0.66	1.61
20-29	0.52	0.26	1.61	1.56	3.95
30-39	0.67	0.30	1.93	1.90	4.81
40-49	0.71	0.32	2.21	2.11	5.34
50-59	0.73	0.32	2.41	2.26	5.71
60-69	0.73	0.33	2.47	2.30	5.83
70-79	0.73	0.33	2.49	2.32	5.87
80+	0.74	0.33	2.49	2.32	5.88
<b>Total male</b>	<b>0.53</b>	<b>0.24</b>	<b>1.70</b>	<b>1.61</b>	<b>4.07</b>
<b>Female</b>					
0-9	0.01	0.00	0.05	0.13	0.19
10-19	0.21	0.56	1.08	1.73	3.58
20-29	0.70	1.53	2.80	3.99	9.02
30-39	0.89	1.70	3.14	4.55	10.29
40-49	0.94	1.73	3.41	4.82	10.90
50-59	0.96	1.74	3.61	5.00	11.30
60-69	0.96	1.74	3.67	5.06	11.43
70-79	0.96	1.74	3.69	5.07	11.48
80+	0.96	1.74	3.70	5.08	11.49
<b>Total female</b>	<b>0.71</b>	<b>1.36</b>	<b>2.70</b>	<b>3.82</b>	<b>8.60</b>
<b>Total persons</b>	<b>0.62</b>	<b>0.81</b>	<b>2.21</b>	<b>2.73</b>	<b>6.37</b>

Source: Deloitte Access Economics calculations based on Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019), United States Census Bureau (2018). Note: components may not sum to totals due to rounding.

Based on current lifetime prevalence, incidence and mortality data, **it was estimated that 28.8 million Americans alive in 2018-19 will have an ED at some point of their life** – either in the past, present or future.<sup>55</sup> As 21.0 million people have had an ED during their life (past and present), 7.8 million Americans alive in 2018-19 will develop an ED in the future. Of new these new cases in the future, approximately 1.9 million will occur in children and adolescents before they are 20 years old.<sup>56</sup>

<sup>55</sup> This result is comparable with previous estimates that suggested 30 million lifetime cases among Americans. See for example, Pater, J. A., Reining, L. E., Miller, A. D., Toscos, T., & Mynatt, E. D. (2019, May). "Not just girls" Exploring Male-related Eating Disordered Content across Social Media Platforms. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (pp. 1-13).

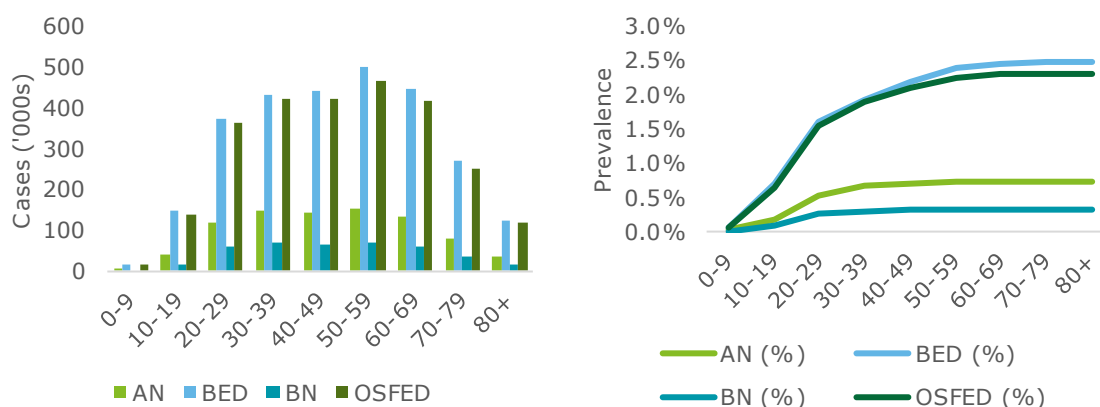
<sup>56</sup> Expected cases in the future were modelled under a period life table approach, where mortality and incidence were assumed to be constant over time. It is also possible to use a cohort life table approach, where it is expected that mortality rates may improve over time and incidence rates may vary too. Both approaches involve an element of uncertainty regarding future mortality and incidence rates, which were both assumed to be constant in the modelling. Given incidence is higher in younger age groups (e.g. see Chart 2.3 and Chart 2.4), there will likely only be a small difference between the two approaches.

Table 2.7: Lifetime prevalent cases: number of affected individuals ('000s), by condition, gender and age, 2018-19

Gender / age (years)	AN	BN	BED	OSFED	Total
<b>Male</b>					
0-9	4.1	0.0	14.5	14.5	33.2
10-19	39.6	16.8	148.1	140.6	345.1
20-29	120.9	60.3	375.6	363.2	920.0
30-39	149.9	67.7	431.8	423.6	1,073.1
40-49	142.9	63.7	443.2	423.8	1,073.5
50-59	151.6	67.4	501.2	469.9	1,190.2
60-69	133.4	59.3	449.2	418.7	1,060.6
70-79	79.8	35.4	270.2	251.4	636.8
80+	37.1	16.5	125.7	116.9	296.2
<b>Total male</b>	<b>859.2</b>	<b>387.1</b>	<b>2,759.5</b>	<b>2,622.7</b>	<b>6,628.6</b>
<b>Female</b>					
0-9	1.4	0.1	9.4	26.2	37.2
10-19	43.3	115.6	221.2	355.3	735.5
20-29	156.1	339.6	623.7	887.5	2,007.0
30-39	196.4	374.7	691.7	1,001.1	2,263.9
40-49	191.6	353.9	695.0	983.5	2,224.1
50-59	207.7	378.3	783.8	1,085.9	2,455.6
60-69	192.9	349.7	736.8	1,014.3	2,293.7
70-79	124.3	225.1	476.8	655.0	1,481.2
80+	75.9	137.4	291.6	400.3	905.3
<b>Total female</b>	<b>1,189.8</b>	<b>2,274.6</b>	<b>4,530.0</b>	<b>6,409.1</b>	<b>14,403.5</b>
<b>Total persons</b>	<b>2,049.1</b>	<b>2,661.7</b>	<b>7,289.5</b>	<b>9,031.8</b>	<b>21,032.0</b>

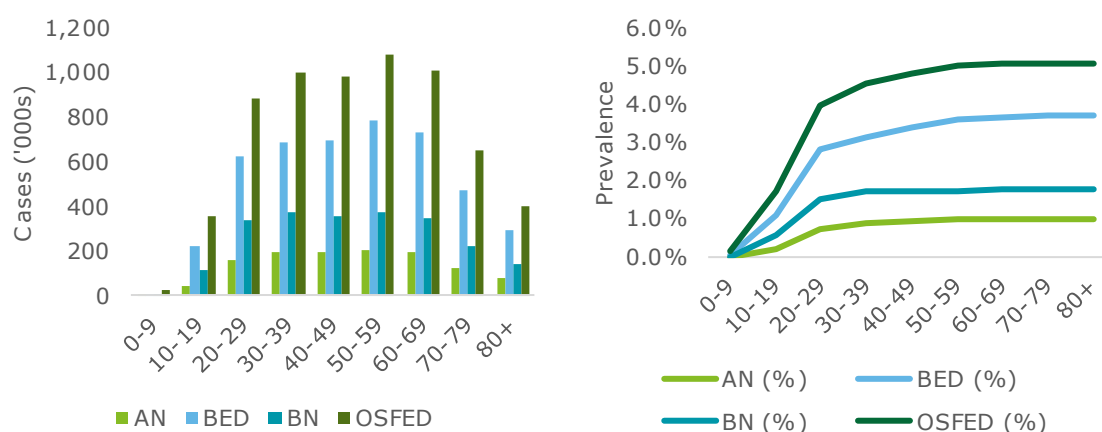
Source: Deloitte Access Economics calculations based on Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019), United States Census Bureau (2018). Note: components may not sum to totals due to rounding.

Chart 2.3: Lifetime prevalence of EDs among males, by age (in years) and condition, 2018-19



Source: Deloitte Access Economics calculations based on Galmiche et al. (2019), Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019).

Chart 2.4: Lifetime prevalence of EDs among females, by age (in years) and condition, 2018-19



Source: Deloitte Access Economics calculations based on Galmiche et al. (2019), Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019).

Table 2.8 provides a comparison between the estimated prevalence across selected studies. As with one-year prevalence, it is possible the rates presented in this study are conservative compared to other nationally representative sources in the US. For example, Hudson et al. (2007)<sup>57</sup> reported higher lifetime rates of BN (0.5% for males, 1.5% for females) and BED (2.0% for males, 3.5% for females) among the adult population. Galmiche et al. (2019)<sup>58</sup> found a lifetime prevalence of 2.2% among males and 8.4% among females.

Table 2.8: Comparison with other published lifetime prevalence estimates

Study	AN (%)	BN (%)	BED (%)	OSFED (%)
Hudson et al. (2007)	0.60 (SE 0.20)	1.00 (SE 0.20)	2.80 (SE 0.40)	Not provided
Udo and Grilo (2018)	0.80 (SE 0.07)	0.28 (SE 0.03)	0.44 (SE 0.05)	Not provided
Galmiche et al. (2019) <sup>59</sup>	0.81	1.26	1.91	3.96
Deloitte Access Economics	0.62	0.81	2.21	2.73

Source: Deloitte Access Economics analysis based on Hudson et al. (2007), Udo and Grilo (2018), Galmiche et al. (2019).

## 2.4 Prevalence projections

In order to project prevalence to 2030, one-year prevalence stratified by condition, age and gender were multiplied by the matched population forecast by the US Census Bureau (2018),<sup>60</sup> assuming no change in prevalence over time.

Assuming no change in prevalence, demographic trends suggest that the number of ED cases will increase from 5.48 million in 2019 to 5.75 million in 2029-30, growth of 4.9% (Table 2.9). While

<sup>57</sup> Hudson, J. I., Hiripi, E., Pope Jr, H. G., & Kessler, R. C. (2007). The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological psychiatry*, 61(3), 348-358.

<sup>58</sup> Galmiche, M., Déchelotte, P., Lambert, G., & Tavolacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: a systematic literature review. *The American journal of clinical nutrition*, 109(5), 1402-1413.

<sup>59</sup> Galmiche et al. (2019) reported lifetime AN prevalence of 2.8% (0-4.8%) for women and 0.3% (0-0.4%) for men; BN prevalence of 1.5% (0-8.4%) for women and 0.1% (0-1.3%) for men; BED prevalence of 2.3% (0-9.8%) for women and 0.3% (0-0.5%) for men; and 10.1% (0.5-31.1%) for women and 0.9% (0-1.7%) for men.

<sup>60</sup> United States Census Bureau. (2018). National Population Projections 2017. Retrieved from <<https://www.census.gov/data/datasets/2017/demo/popproj/2017-popproj.html>>.

this reflects an estimated increase in the number of cases, it also reflects a declining percentage of the population – with the prevalence of EDs as a share of the total population expected to decline from 1.66% in 2018-19 to 1.62% in 2029-30.

Table 2.9: Prevalence projections ('000s and %) by gender, condition and year

Gender / condition	2018-19	2022-23	2025-26	2029-30
<b>Male</b>				
AN	139.6	141.9	143.3	144.8
BN	89.0	90.0	90.7	92.0
BED	426.8	437.7	445.7	457.6
OSFED	437.1	446.2	452.9	462.8
<b>Total male</b>	<b>1,092.5</b>	<b>1,115.7</b>	<b>1,132.7</b>	<b>1,157.3</b>
<b>Total male (%)</b>	<b>0.67</b>	<b>0.67</b>	<b>0.66</b>	<b>0.66</b>
<b>Female</b>				
AN	268.4	274.4	278.0	282.0
BN	532.9	535.9	538.5	544.6
BED	1,606.5	1,642.0	1,665.5	1,693.2
OSFED	1,980.3	2,014.8	2,038.8	2,070.4
<b>Total female</b>	<b>4,388.1</b>	<b>4,467.1</b>	<b>4,520.8</b>	<b>4,590.2</b>
<b>Total female (%)</b>	<b>2.62</b>	<b>2.59</b>	<b>2.57</b>	<b>2.55</b>
<b>Persons</b>				
AN	408.0	416.3	421.3	426.8
BN	621.9	625.8	629.3	636.7
BED	2,033.3	2,079.7	2,111.2	2,150.8
OSFED	2,417.4	2,461.0	2,491.8	2,533.2
<b>Total</b>	<b>5,480.6</b>	<b>5,582.8</b>	<b>5,653.5</b>	<b>5,747.5</b>
<b>Total (%)</b>	<b>1.66</b>	<b>1.64</b>	<b>1.63</b>	<b>1.62</b>

Source: Deloitte Access Economics calculations based on Udo and Grilo (2018), Galmiche et al. (2019), Alegria et al. (2016), Glazer et al. (2019), Rozzell et al. (2019), Ward et al. (2019), United States Census Bureau (2018). Note: components may not sum to totals due to rounding.

## 2.5 Mortality

Evidence suggests that EDs are associated with excess premature mortality,<sup>61</sup> and EDs are among the highest case fatality rates of any mental illness.<sup>62</sup> Notably, AN is estimated to have the highest

<sup>61</sup> Official mortality estimates may understate the true number of deaths due to EDs. EDs often go undetected and undiagnosed, and the cause of death among individuals with an ED may be recorded as some other factor (for example, heart failure) rather than the underlying disorder, here an ED.

<sup>62</sup> This refers to the case fatality rate, which differs from the cause-specific (crude) mortality rate. The case fatality rate is a ratio of total deaths due to a condition to the total number of diagnosed cases of that condition. The cause-specific (crude) mortality rate is a ratio of deaths due to a condition divided by the US population. The cause-specific (crude) mortality rate is thus likely to be much lower than the case fatality rate. While EDs are reported to have the highest case fatality rate of any mental illness, some other mental illnesses may have a higher cause-specific (crude) mortality rate, which is measured as a ratio of deaths due to a condition divided by the total US population.

Smink, F. R., Van Hoeken, D., & Hoek, H. W. (2012). Epidemiology of eating disorders: incidence, prevalence and mortality rates. *Current psychiatry reports*, 14(4), 406-414.



case fatality rate of all EDs.<sup>63</sup> Around 20% of those that experience AN die by suicide and others die as a result of natural causes related to AN.<sup>64</sup> One study estimated that students with high levels of ED symptoms were 11 times more likely to attempt suicide relative to students with no ED symptoms.<sup>65</sup> Other US studies based on representative adolescent survey cohorts have found suicidal ideation among 53% of adolescents with BN, and 34% among adolescents with BED<sup>66</sup>. Mortality in EDs also increases when there is a low body mass index (BMI) and alcohol problems.<sup>67</sup>

For the purpose of this report, a literature review was conducted to quantify the excess risk of mortality associated with each specific ED. The most representative study was found to be a meta-analysis by Arcelus et al. (2011).<sup>68</sup>

Arcelus et al. (2011) performed a meta-analysis of 36 quantitative studies of mortality in EDs. Each of the included studies followed 15 or more participants for a minimum of one year. Overall, there were over 17,000 people with EDs, and over 750 deaths were covered by the analysis. The authors calculated standardized mortality ratios (SMRs)<sup>69</sup> including 5.86 for AN, 1.93 for BN, and 1.92 for EDNOS.

While Arcelus et al. (2011) was found to be the most representative study for the purposes of estimating excess mortality, a scan of available literature was conducted with the findings from further studies summarized below. The excess mortality rates estimated in these studies fall within the range reported by Arcelus et al. (2011).

- Demmler et al. (2020)<sup>70</sup> examined the burden of EDs in the United Kingdom population in terms of survival using electronic health records from general practitioner and hospital admissions. Based on a cohort of individuals who received an ED diagnosis between 1990 and 2017, crude hazard rates for mortality were estimated by condition ranging from 2.33 for AN, 1.82 for other EDs, 1.41 for BN, and an overall rate of 1.87. The leading cause of death among these individuals was diseases of the respiratory system, followed by injury, poisoning and other external causes.
- Fitcher et al. (2016)<sup>71</sup> conducted a large cohort-based study of 5,839 consecutively admitted inpatients in Germany. Of these patients, 1,639 were treated for AN, 1,930 for BN, 363 for BED, and 1,907 for EDNOS. Based on follow-up of these individuals, SMRs were estimated, which ranged from 5.35 for AN, 1.49 for BN, 1.50 for BED, and 1.70 for widely defined EDNOS. It was also found that patients with AN died earlier than individuals with other EDs. Risk factors were identified, including chronicity, later age of onset, not living in a relationship, and in an irregular type of discharge from index inpatient treatment. Suicidality was found to be a univariate predictor of a shorter time to death in BN only, while those with AN mostly died from natural causes related to their condition.

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<sup>63</sup> Arcelus J, et al.. Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. *Arch Gen Psychiatry*. 2011;68(7):724-31.

<sup>64</sup> Ibid.

<sup>65</sup> Lipson, S. K., & Sonnevile, K. R. (2020). Understanding suicide risk and eating disorders in college student populations: Results from a National Study. *Int J Eat Disord*, 53(2), 229-238.

<sup>66</sup> Crow, S. J., Swanson, S. A., Le Grange, D., Feig, E. H., & Merikangas, K. R. (2014). Suicidal behavior in adolescents and adults with bulimia nervosa. *Comprehensive psychiatry*, 55(7), 1534-1539.

<sup>67</sup> Button, E. J., Chadalavada, B., & Palmer, R. L. (2010). Mortality and predictors of death in a cohort of patients presenting to an eating disorders service. *International Journal of Eating Disorders*, 43(5), 387-392.

<sup>68</sup> Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies. *Archives of general psychiatry*, 68(7), 724-731.

<sup>69</sup> The SMR is a ratio between the observed number of deaths in a study population and the number of deaths that would be expected, based on the age- and gender-specific rates in a standard population and the population size of the study population by the same age/gender groups.

<sup>70</sup> Demmler, J. C., Brophy, S. T., Marchant, A., John, A., & Tan, J. O. (2020). Shining the light on eating disorders, incidence, prognosis and profiling of patients in primary and secondary care: national data linkage study. *The British Journal of Psychiatry*, 216(2), 105-112.

<sup>71</sup> Fichter, M. M., & Quadflieg, N. (2016). Mortality in eating disorders-results of a large prospective clinical longitudinal study. *International Journal of Eating Disorders*, 49(4), 391-401.

In the absence of evidence quantifying the excess mortality associated with BED, it was assumed that it would be comparable to EDNOS (1.92).<sup>72</sup>

Table 2.10: SMRs by type of ED

Condition	SMR
AN	5.86
BN	1.93
BED	1.92
OSFED	1.92

Source: Arcelus et al. (2011).

Most studies conducted on the excess mortality associated with EDs are focused on a sample based on younger and middle aged population groups. As people age beyond 65 years, underlying all cause mortality rates exhibit a significant increase thereby diminishing the excess mortality attributable to EDs. Given the increase in all cause mortality rates beyond 65 years of age, the SMRs were conservatively applied to only the working age population – those aged from 15 to 64 years of age.<sup>73</sup>

The SMRs published by Arcelus et al. (2011)<sup>74</sup> were then multiplied by the 2018-19 US mortality rates by age and gender and multiplied by the matched one-year prevalence for each type of ED.

Overall, it was estimated that there were approximately 10,200 deaths in the US associated with EDs in 2018-19<sup>75</sup>. More deaths were associated with OSFED (approximately 3,430 deaths or 33% of the total deaths due to EDs) than any other ED, noting the greater prevalence of the condition driving that result. Using the standard errors published in Arcelus et al. (2011) as lower and upper bounds, it was found that the number of excess deaths due to EDs in the US may range from around 5,500 to 22,200 in 2018-19.

<sup>72</sup> Elsewhere in this report, the impacts of OSFED were largely equated with BED as prevalence studies indicated that OSFED-BED makes up the largest share of total OSFED, based on evidence available in Dahlgren et al (2017).

<sup>73</sup> This assumption was based on the mean age and years of follow up reported across studies included in Arcelus et al. (2011). For example, for AN, the mean age at assessment was generally between 15 and 25 years old, while follow up occurred for between 6 and 35 years. Similarly, for BN, the mean age at assessment was generally between 15 and 25 years, while follow up occurred for up to 20 years. Finally, for other EDs, the mean age at assessment was between 25 and 35 years old, with follow up occurring for up to 17 years. Applying the SMRs to all-cause mortality ratios in older adults would excessively attribute deaths to EDs in older adults given the competing risk of mortality due to other causes, so these effects were conservatively excluded given the lack of evidence in older adults.

<sup>74</sup> Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies. *Archives of general psychiatry*, 68(7), 724-731.

<sup>75</sup> The SMRs published by Arcelus et al. (2011) do not all control for confounding factors (for example, comorbid conditions) which may result in higher mortality rates for individuals with EDs. Therefore, this estimated mortality reflects the estimated deaths associated with EDs rather than only those deaths which are due to an underlying cause of ED.

Table 2.11: Excess deaths associated with EDs, by condition, gender and age, 2018-19

Age (years)/gender	AN	BN	BED	OSFED	Total
<b>Male</b>					
15-19	60	10	30	30	130
20-29	390	40	120	150	700
30-39	380	40	70	120	610
40-49	60	40	140	120	360
50-59	100	90	340	300	830
60-64	120	10	310	220	660
<b>Total (male)</b>	<b>1,110</b>	<b>230</b>	<b>1,010</b>	<b>940</b>	<b>3,290</b>
<b>Female</b>					
15-19	40	20	40	60	160
20-29	260	90	260	310	920
30-39	340	80	330	380	1,130
40-49	190	150	260	350	950
50-59	330	370	640	850	2,190
60-64	410	40	570	540	1,560
<b>Total (female)</b>	<b>1,570</b>	<b>750</b>	<b>2,100</b>	<b>2,490</b>	<b>6,910</b>
<b>Total (persons)</b>	<b>2,680</b>	<b>980</b>	<b>3,110</b>	<b>3,430</b>	<b>10,200</b>

Source: Deloitte Access Economics calculations based on Arcelus et al. (2011), Arias et al. (2019). Note: components may not sum to totals due to rounding.

## 3 Case studies

As part of the project, the Strategic Training Initiative for the Prevention of Eating Disorders, in collaboration with the Cambridge Eating Disorders Center, undertook interviews with 10 people with EDs or their caregivers. Each interview sought to assess the impact of EDs on the individual, their families, and society more broadly. The interviews were summarized, with the purpose of narrating the personal, social and economic consequences of EDs.<sup>76</sup>

The interviews covered topics such as:

- The demographics of the participant (and their family member)
- The impact of the ED on the individual, including how long the individual had been living with an ED
- What kinds of treatment the individual received, and what challenges may have been present with accessing care specifically for their ED.

Interview recordings were provided to Deloitte for the results to be synthesized and included in this report. The following three case studies capture what is believed to be all too common scenarios that are faced by the millions of people living with the impacts of EDs in the US today.

### 3.1 Case study – Carolyn and Hannah’s story

Carolyn, a white woman and mother of three was living in Hawaii in 2013. Her husband, who served in the military for 22 years, was posted on short notice to Germany later that year. At the time, their daughter Hannah was 13 years old, and Carolyn noted that this was a formative period in her psychosocial development. Carolyn described the move to Germany as a dramatic change for Hannah, after which she was unable to connect with friends and increasingly became aware of her body image.

From August 2013 to January 2014, Hannah rapidly lost more than a third of her body weight. Carolyn and Hannah visited a physician at the Landstuhl Regional Medical Center operated by the US Army. In December, Hannah was diagnosed with severe AN. In January, they had a follow up appointment with her primary care provider, following which Hannah was referred to a hospital due to complications from her ED (low heart rate). Carolyn and Hannah were flown back to Washington, DC, on a medevac as they were unable to see a pediatric cardiologist in Germany.

Carolyn’s daughter received two weeks of stabilization care at the Walter Reed Army Medical Center. After Hannah was well enough, they moved to a hospital in Virginia where Hannah received inpatient care for the next four and a half months.

After being discharged Carolyn and Hannah chose to move to San Antonio, Texas, a place where Hannah had positive memories. Hannah was transitioning to IOP care, although she then experienced a relapse. During Hannah’s relapse, she required higher level care and her medical costs were approximately \$910 per day. This treatment was necessary, but it was not covered under their TRICARE insurance plan. Carolyn noted that this placed a significant financial burden on the family. Carolyn spent approximately \$10,000 in one month. Altogether, 13 months of inpatient and IOP treatment ultimately contributed to Hannah’s recovery.

*“As a military family we had access to TRICARE insurance, however intensive outpatient care was not covered, which was a significant financial burden. Asking staff how people could afford this care they said often second mortgages were taken, dipping into college savings plans. We had neither of these. As a military family we had moved 11 times in 22 years.”*

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<sup>76</sup> All of the case study participants reviewed and consented to disclosure of the content in this chapter.

Today Hannah has fully recovered from her condition, although she missed a year of school while receiving treatment. Hannah has received additional tutoring to catch up to her peers. Hannah now has a healthy body image and has discontinued individual therapy.

*"The emotional toll of the condition was significant. Our family was separated for one year across continents. As a family of five, we each blamed ourselves, thinking that we were the problem that may have resulted in Hannah nearly losing her life. We learned however that an eating disorder was not a choice. We understand that anorexia nervosa is such a harmful psychiatric illness."*

Carolyn has been campaigning to provide additional supports to other families with EDs. Since her family's battle for coverage, federal regulations precluding TRICARE from covering IOP care in a freestanding facility have been lifted. However, barriers still exist for residential eating disorders treatment, including a prohibition against military families over the age of 20 years old receiving treatment and administrative barriers for freestanding facilities to contract with TRICARE.

It is Carolyn's desire to: *"Enable all military families affected by eating disorders to access affordable care under TRICARE."*

### 3.2 Case study – Darian's story

Darian is a 26-year-old Latina currently in recovery from BED. She had been receiving therapy over the last 6 years. Darian's condition was triggered by childhood trauma when she was 9 to 12 years of age.

Darian was afraid to seek help for her ED. Darian relied upon outpatient care as she was unable to pay for residential care and did not have insurance that would cover it. Furthermore, Darian wanted to remain "in the closet" about her condition due to the stigma and shame regarding mental illness. Darian articulated, "Mental illness in my community is not mentioned or spoken about openly. If someone is struggling with mental illness, we have to hide or wear a mask; we were not told there is another way to live." Accordingly, she kept her ED secret from her parents, which meant that she could not receive residential treatment under her parent's insurance plan. The significant cost of residential care, and Darian's lack of available insurance to cover it meant that the treatment of Darian's ED was delayed.

Given Darian's financial constraints, Darian had sought therapy from her church community and from other therapists not specializing in treating EDs. She found that these people were not able to provide adequate support as they did not properly understand the disorder.

*"The emotional toll was significant. I often felt belittled when I dealt with clinicians who were not competent in the treatment of my condition."*

Given the stigma attached to EDs, she often experienced internal shame as a result of her condition. Darian even noted that she felt this way at family gatherings, where she would engage in BED behavior.

*"Food is central to love and family in the Latin American community. When I was suffering alone as a sick person who binges, I often felt worthless."*

*"Continually being compared to my cousins because of my size took an emotional toll. Given the fact that as Latino Americans we don't have a high degree of representation in the media, I was constantly expected to look a certain way, which was not representative of who I was."*

At the age of 22, Darian volunteered with the Alliance for Eating Disorders Awareness in Florida, which was critical to enabling her to better understand herself and her condition. Through the Alliance, which offers very low cost treatment services for people with financial need, Darian connected with a specialized therapist who properly understood her condition and provided her with the necessary support she needed to recover from her ED.

Darian has reflected that there needs to be an overhaul in the public's understanding of EDs and the pathways of care for individuals and the respective care plans. Darian believes it is critical to change the narrative around how communities of color both psychologically internalize their

struggle with mental illness individually and address intergenerational trauma within the community. It is only then that the impact of EDs will be reduced.

### 3.3 Case study – Andrew’s story

Andrew is a 47-year-old white man born and raised in Maryland. Andrew has suffered from a variety of EDs, including AN, BN and BED, with the earliest ED first appearing when he was around 10 years old. Andrew experienced loneliness, depression and neglect as a child, and he used food to self-soothe. When Andrew was in fifth grade, he was bullied by his peers and told by his family that he needed to lose weight. Andrew was given gym memberships and weight loss programs, during which he experienced a series of binge-restrict episodes that led to further weight gain. As his weight gain continued, Andrew’s father said, *“Son, I’m so sorry. I’ve failed as a father. I’ve let you get so fat.”*

Andrew began a medically supervised diet and was told by his father that if he didn’t lose enough weight, that child support would be withheld. Andrew felt as though he had failed his dad, and he was determined to meet the weight loss goals. He began restricting his caloric intake to a third of what was recommended, and he developed compulsive exercise behavior. During this time Andrew developed symptoms of bulimia and engaged in cycles of bingeing and purging. Though Andrew lost the weight, he still saw “a grotesquely fat person” when looking in the mirror. Andrew dropped out of school at age 19 and returned home. He was depressed and unable to keep a job, and he turned strictly to binge-eating. At age 20 Andrew visited a psychiatrist. Despite telling him about his thoughts of body image, self-loathing and crash-dieting, Andrew was diagnosed with depression with no mention of EDs. Andrew’s therapy was funded out-of-pocket by his mother, at a cost of \$300 per session. She continued to pay for sessions every few months for the next 4 years.

Andrew went to Berklee College of Music in Boston, where it was reinforced in his mind that larger people had no place in music. He was told “there are no fat white men in pop music. You have to lose weight if you want to be successful.” Andrew felt like he never had a shot at his true goal of being a performing musician.

*“Nobody is going to really want me... I can be the person behind the scenes where I belong.”*

Andrew graduated from Berklee College and moved to Nashville, Tennessee, at the age of 23. He found a psychiatrist and a therapist to continue care of his depression. Neither picked up that he had an ED, and Andrew felt “completely unheard.”

To lose weight, Andrew began restricting calories again and became a compulsive runner. He ran so much that he wore out the cartilage in his hip, so much so that his doctor said he would need a hip replacement by the time he was 25. At this point Andrew transitioned to compulsive weight lifting. He lifted weights so often that he tore both rotator cuffs, rendering him unable to lift any weight. This led to more severe bouts of depression, and his psychiatrist provided a different medication to treat his depression.

When Andrew was 30 he had a severe panic attack related to a binge episode at which point his wife encouraged him to seek help for his suspected ED. Andrew searched for a care provider and found only one who was covered under his Blue Cross Blue Shield insurance. After three months of treatment with his provider, she stopped accepting commercially insured patients and she was not willing to continue seeing Andrew on a reduced fee basis. Andrew had no money for care, there were no specialists available under his insurance and no support groups that allowed men to participate. His only option was to see a dietitian who saw him on “low bono” rates of \$20 per week. Andrew reflected:

*“My treatment course was absolutely delayed by lack of finance, options and gender inequality that existed.”*

Andrew saw his dietitian for 2 years, beyond which he spent several years continuing to work through his ED problems on his own. Andrew is now recovered and is an ED specialist who takes insurance and specializes in male EDs – the only one in Maryland and Washington D.C.

## 4 Financial costs

### Key findings

- The total health system costs associated with EDs in the US were estimated at \$4.6 billion in 2018-19. OSFED accounted for the largest share of costs (\$1.5 billion), followed by BED (\$1.2 billion), AN (\$1.1 billion), and BN (\$0.8 billion). The estimated average cost per person was highest for individuals with AN (\$2,615), followed by those with BN (\$1,335).
- Overall, the total costs of EDs outside the health system was estimated to be \$60.2 billion in the US in 2018-19, or \$10,977 per American with an ED. Including health system costs, the financial costs of EDs in 2018-19 were estimated to be \$64.7 billion, or \$11,808 per person with an ED. The largest share of these costs was accounted for by OSFED (\$22.8 billion, or 35%), followed by BED (\$19.4 billion, or 30%), BN (\$11.4 billion, or 18%) and AN (\$11.2 billion, or 17%).
- Productivity losses for people with EDs were estimated to be \$48.6 billion. Of the productivity losses, reduced employment accounted for \$15.2 billion (31%), and premature mortality, absenteeism and presenteeism accounted for \$8.8 billion (18%), \$6.4 billion (13%) and \$18.2 billion (37%), respectively (Chart 4.2). Of the total productivity costs, 37.9% was borne by individuals, 28.6% was borne by government and 33.6% was borne by employers.
- The total cost of informal care due to EDs was calculated to be \$6.7 billion in 2018-19, which equated to an average annual cost of \$1,228 per person with an ED. Efficiency losses were estimated at \$4.8 billion, or an average annual cost of \$875 per individual with an ED in 2018-19.

#### 4.1 Health system costs

An individual with an ED is likely to access health services as a result of their condition. These services may include visits to a mental health practitioner, or a primary care provider, seeking help from a nutritionist or dietitian, and in more severe cases accessing care in an inpatient hospital or emergency department setting.

This section describes the approach used to estimate the health system costs associated with EDs in the US in 2018-19.

##### 4.1.1 Summary of approach

Health system costs include health services delivered in a primary or outpatient setting, hospital and emergency department services, diagnostic tests, pharmaceuticals, vitamins and supplements, and medical research.

These costs were disaggregated by payer according to data provided by the CMS National Health Expenditure Accounts,<sup>77</sup> and the Agency for Healthcare Research and Quality (AHRQ) inpatient hospitalizations<sup>78</sup> by source of payer. Across both sources, the leading payer was private health insurer, followed by government programs such as Medicare and Medicaid.

A scan of literature and administrative sources was conducted to identify sources that would enable estimation of the health system costs associated with EDs in the US. For the purposes of this study, state specific administrative sources were not considered to be nationally representative, and as such these were excluded from more detailed analysis.

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<sup>77</sup> CMS (2019). National Health Expenditure Accounts: Historical Data. Retrieved from <<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical>>.

<sup>78</sup> Agency for Healthcare Research and Quality (AHRQ) (2016). Healthcare cost and utilization project. Retrieved from <<https://hcupnet.ahrq.gov>>.

While a nationally representative estimate of the hospital and emergency department costs associated with EDs was located, the estimate of other health system costs relied on a bottom-up approach in the absence of representative data.

#### **4.1.2 Inpatient and emergency department visits**

This section estimates the costs of inpatient or emergency department visits due to EDs. The costs captured in this section incorporate both inpatient stays where an ED was the primary diagnosis, as well as secondary diagnoses where an ED is likely to be an underlying cause of hospitalization.

A common limitation found in available evidence was the use of insured individuals or individuals covered by a health plan as the basis of analysis. These sources may overstate the underlying health resource utilization if applied across the insured and non-insured populations alike, since insured individuals are likely to utilize more services. This is because not all people with an ED may have a health insurance plan or be covered by employer-funded health plans. Additionally, ED conditions may not be covered by all health plans across the US. Moreover, not all health plans or insurance policies cover all ED conditions (for example, some may cover AN but not BED).

The most nationally representative source located for hospitalization and emergency department costs due to EDs was found to be the HCUPNet database published by the AHRQ (2016)<sup>79</sup>, which captures all individuals who accessed services, irrespective of the source of payment. This database relies on the National Inpatient Sample (NIS), which approximates 20% of discharges from all US community hospitals and is the largest publicly-available all-payer database in the US. The AHRQ publishes weighted national estimates from the NIS, based on data collected by individual states and provided to the AHRQ by the states. The sample is updated annually based on data from over 7 million inpatient stays. The AHRQ publishes data by ICD-10 condition on inpatient stays, ambulatory surgery and emergency department admissions in the US.

#### **Inpatient stays**

Inpatient stays for EDs were found by Owens et al. (2019)<sup>80</sup> to be the costliest at a hospitalization cost of \$19,400 per admission and longest type of stays for mental and substance use disorders, with an average length of stay of 13.6 days. This compared to costs of \$8,900 for schizophrenia, and \$8,800 for alcohol-related disorders.<sup>81</sup>

The AHRQ (2016)<sup>82</sup> reported that in 2016, there were 5,425 hospitalizations relating to a primary diagnosis of an ED. The total cost associated with these hospitalizations was reported to be \$107.6 million.

These estimates were adjusted for prevalence growth from 2016 to 2018-19, and the change in hospitalization costs as a result of health inflation.<sup>83</sup> Overall, it was calculated that there were 5,609 hospitalizations in 2018-19 where an ED was listed as the primary cause. This yielded a total cost estimate of \$116.8 million, or an average cost per discharge of \$20,817.

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<sup>79</sup> Agency for Healthcare Research and Quality (AHRQ). (2016). Healthcare cost and utilization project. Retrieved from <<https://hcupnet.ahrq.gov>>.

<sup>80</sup> Owens PL, Fingar KR, McDermott KW, Muhuri PK, Heslin KC. (2019). Inpatient Stays Involving Mental and Substance Use Disorders, 2016. HCUP Statistical Brief #249. Agency for Healthcare Research and Quality, Rockville, MD. Retrieved from [www.hcup-us.ahrq.gov/reports/statbriefs/sb249-Mental-Substance-Use-Disorder-Hospital-Stays-2016.pdf](http://www.hcup-us.ahrq.gov/reports/statbriefs/sb249-Mental-Substance-Use-Disorder-Hospital-Stays-2016.pdf).

<sup>81</sup> Owens PL, Fingar KR, McDermott KW, Muhuri PK, Heslin KC. (2019). Inpatient Stays Involving Mental and Substance Use Disorders, 2016. HCUP Statistical Brief #249. Agency for Healthcare Research and Quality, Rockville, MD. Retrieved from [www.hcup-us.ahrq.gov/reports/statbriefs/sb249-Mental-Substance-Use-Disorder-Hospital-Stays-2016.pdf](http://www.hcup-us.ahrq.gov/reports/statbriefs/sb249-Mental-Substance-Use-Disorder-Hospital-Stays-2016.pdf).

<sup>82</sup> Agency for Healthcare Research and Quality (AHRQ). (2020), Healthcare cost and utilization project (HCUP). Retrieved from <<https://www.ahrq.gov/data/hcup/index.html>>.

<sup>83</sup> Centers for Medicare and Medicaid Services (CMS). (2019). Personal Health Care (PHC) indices – overall. Retrieved from <<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/Tables.zip>>.



It is also important to incorporate the cost of hospitalizations related to a secondary diagnosis of an ED, where the ED was likely to be an underlying cause of admission<sup>84</sup>. In 2019, there were an estimated 33,989 inpatient hospitalization stays where an ED was listed as a secondary cause.

The AHRQ (2009)<sup>85</sup> reported that mood disorders were the most common primary diagnosis where EDs were recorded as a secondary or additional diagnosis, and so the average hospitalization costs for mood disorders (\$6,007 in 2019 terms) – where they are listed as the primary cause – were used as the basis of the unit costs for admissions where EDs are listed as a secondary diagnosis (the eating disorder will contribute to the cost, but not be entirely responsible for the total cost of the hospitalization). In attributing these costs to the component related to EDs, the total average cost per case was divided by the average number of comorbidities (2.20)<sup>86</sup> experienced by an individual with an ED. The adjusted cost of inpatient stays due to EDs as a secondary cause was estimated to be \$2,743.

The average cost per discharge was then multiplied by the estimated number of hospitalizations in 2018-19 where an ED was a listed cause to estimate total hospitalization costs due to EDs, which came to \$209.7 million (\$116.8 million due to primary cause stays, and \$92.9 million due to secondary cause stays).

Table 4.1: Cost of hospitalizations due to EDs, US 2018-19

Hospitalization	Average cost per discharge (\$)	Number of discharges	Total cost (\$ million)
Primary cause	20,817	5,609	116.8
Secondary cause	2,743	33,989	92.9
<b>Total</b>			<b>209.7</b>

Source: AHRQ (2009, 2016), Deloitte Access Economics modelling. Note: components may not sum to totals due to rounding.

Given limitations with the available data, it was assumed that the distribution of these hospitalization costs by condition were the same across primary and secondary diagnosed cases, according to the number of discharges. The breakdown of hospital costs by type of ED is provided in Table 4.2. The average cost per person with an ED is also provided, which was derived by dividing the total cost for each condition by the estimated prevalence by type of ED from chapter 2 of this report.

<sup>84</sup> Individuals admitted to hospital may have received a primary diagnosis (for example, mood disorder, substance abuse disorder or heart failure) where an ED is the underlying cause of the hospitalization. Since the ED is the underlying cause behind hospitalization, it is important to incorporate these costs.

<sup>85</sup> Zhao, Y., & Encinosa, W. (2011). An update on hospitalizations for eating disorders, 1999 to 2009: Statistical brief# 120. Rockville: Healthcare Cost and Utilization Project (HCUP) Statistical Briefs.

<sup>86</sup> Swanson et al. (2011) analysed the prevalence and correlates of eating disorders based on a nationally representative sample of 10,123 adolescents in the United States. The study found that individuals with an eating disorder also commonly experienced multiple cross-class comorbidities, with comorbidities including mood disorder or anxiety disorder. Based on the results of this study, it was calculated that an individual with an eating disorder had an average of 2.20 comorbidities.

Table 4.2: Breakdown of annual hospitalization costs by condition, US 2018-19

Condition	Total cost (\$ million)	Average cost per person with an ED (\$)
AN	134.8	330
BN	43.0	69
BED	14.4	7
OSFED	17.5	7
<b>Total / weighted average</b>	<b>209.7</b>	<b>38</b>

Source: AHRQ (2009, 2016), Deloitte Access Economics modelling. Note: components may not sum to totals due to rounding.

### Emergency department

The cost of emergency department visits associated with EDs was estimated following the same approach as for inpatient hospitalization costs. It was found that in 2016 there were 7,858 visits relating to primary diagnosis of an ED, and 44,864 visits where an ED was the secondary diagnosis. This was adjusted for prevalence growth to 8,036 emergency department visits related to primary diagnosis of an ED, and 45,882 emergency department visits related to a secondary diagnosis in 2018-19.

In the absence of data to estimate the cost associated with emergency department visits where an ED was listed as the secondary diagnosis, it was assumed that the same cost applied across both primary and secondary cause visits. The cost of emergency department visit for individuals with an ED was calculated to be \$1,012 based on MEPS data for visits relating to a primary diagnosis. This cost estimate was divided by comorbidity (2.20), yielding an adjusted cost of \$462 attributable to EDs for emergency department visits where an ED was listed as a secondary cause<sup>87</sup>.

The overall total cost was estimated by multiplying the average cost per visit to the estimated number of visits (Table 4.3). The costs of emergency department visits due to an ED in the US in 2018-19 were calculated to total \$29.3 million, comprising \$8.1 million due to visits relating to an ED as a primary cause and \$21.1 million due to visits where an ED was listed as a secondary cause. These costs were largely borne by individuals with AN (\$18.8 million, or 64% of emergency department costs due to EDs). The breakdown by condition was informed based on each condition's relative share of hospital discharges (as in Table 4.2).

Table 4.3: Breakdown of annual emergency department costs by condition, 2018-19

Condition	Total cost (\$ million)	Average cost per person with an ED (\$)
AN	18.8	46
BN	6.0	10
BED	2.0	1
OSFED	2.4	1
<b>Total / weighted average</b>	<b>29.3</b>	<b>5</b>

Source: AHRQ (2009, 2016), Deloitte Access Economics modelling. Note: components may not sum to totals due to rounding.

#### 4.1.3 Primary and outpatient healthcare

Primary and outpatient healthcare services include primary care provider presentations, other allied health services such as dietitians, pediatricians, and internists, specialist procedures such as

<sup>87</sup> Based on results published by Swanson et al. (2011), it was calculated that an individual with an eating disorder had an average of 2.20 comorbidities.

Swanson, S. A., Crow, S. J., Le Grange, D., Swendsen, J., & Merikangas, K. R. (2011). Prevalence and correlates of eating disorders in adolescents: Results from the national comorbidity survey replication adolescent supplement. *Archives of general psychiatry*, 68(7), 714-723.

visits to a mental health practitioner or adolescent medicine specialist that may be conducted in an outpatient setting, and other community-based services.

Based on the literature review conducted (search strings provided in A.2), there was no nationally representative estimate of the primary and outpatient healthcare costs associated with EDs in the US. The sources located had a number of limitations, such as analysis that was restricted to only one of the ED conditions or overrepresentation of a particular condition that was not generalizable to other EDs.

Given limitations with the available data, the costs of primary and outpatient healthcare were separately estimated for AN, BN, BED and OSFED using the most representative approach available for each condition.

### **AN and BN**

For AN and BN, the estimated primary healthcare cost per person was based on Samnaliev et al. (2014)<sup>88</sup>. The authors analyzed data from the MEPS for five years to 2011 to estimate the difference in annual healthcare costs for those individuals with EDs versus those without an ED. It was found that individuals with an ED incurred average additional health system costs of \$1,869 per annum, or \$2,119 per person in 2018-19 terms after adjustment for health inflation.<sup>89, 90</sup>

The figure provided by Samnaliev et al. (2014) captured all health system costs, such as hospitalizations, residential care, and pharmaceuticals, and the authors provided no breakdown by type of cost or across conditions. To disaggregate this cost, it was assumed based on Mitchell et al. (2009)<sup>91</sup> that health system costs were 1.5 times larger for individuals with BN compared to individuals with AN<sup>92</sup>. It was further assumed based on Mitchell et al. (2009) that 40.1% of BN health system costs, and 50.0% of AN health system costs related to primary and outpatient healthcare.

Based on this approach, **the average primary and outpatient cost associated with AN was calculated to be \$841, compared to \$1,031 for an individual with BN.**

### **OSFED and BED**

The MEPS cohort used as the basis for Samnaliev et al. (2014)<sup>93</sup> likely overrepresents individuals with AN and BN, and for the purposes of this report was not considered generalizable to individuals with BED or OSFED.

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<sup>88</sup> Samnaliev et al. (2014). Samnaliev, M., Noh, H. L., Sonnevile, K. R., & Austin, S. B. (2014). The economic burden of eating disorders and related mental health comorbidities: An exploratory analysis using the US Medical Expenditures Panel Survey. *Preventive medicine reports*, 2, 32-34.

<sup>89</sup> Centers for Medicare and Medicaid Services (CMS). (2019). Personal Health Care (PHC) indices – overall. Retrieved from <<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/Tables.zip>>.

<sup>90</sup> Data were accessed from MEPS in order to triangulate the estimates provided by Samnaliev et al. (2014). It was estimated that the average individual with an eating disorder in 2012 accessed 3.25 primary care provider visits in 2012, and 7 mental health practitioner sessions. The costs for these services totalled \$181 million for mental health practitioner visits and \$790 million for visits to primary care providers and other medical professionals across individuals captured by MEPS with an eating disorder in 2012. Due to the small sample size and inability to precisely identify individuals with an ED based on underlying MEPS data, the estimate provided by Samnaliev et al. (2014) was used as the basis for primary and outpatient health system costs among individuals with AN and BN in 2018-19.

<sup>91</sup> Mitchell, J. E., Myers, T., Crosby, R., O'Neill, G., Carlisle, J., & Gerlach, S. (2009). Health care utilization in patients with eating disorders. *International Journal of Eating Disorders*, 42(6), 571-574.

<sup>92</sup> Mitchell et al. (2009) estimated the costs of professional health visits to total \$2,660 for individuals with BN and \$1,720 for individuals with AN in the 12 months following diagnosis based on a cohort study in the United States.

<sup>93</sup> Samnaliev, M., Noh, H. L., Sonnevile, K. R., & Austin, S. B. (2014). The economic burden of eating disorders and related mental health comorbidities: An exploratory analysis using the US Medical Expenditures Panel Survey. *Preventive medicine reports*, 2, 32-34.

In the absence of a representative data source, utilization and frequency of service use were estimated for OSFED and BED and then multiplied by nationally representative unit prices in order to estimate the primary and outpatient healthcare costs for individuals with these EDs.

The CPES<sup>94</sup>, which asked respondents about their lifetime utilization of health resources due to EDs, was found to be the most representative source of health resource utilization data.

For the purposes of this report, the scope was limited to the one-year costs associated with prevalent cases of EDs in 2018-19. As such, the lifetime service utilization rates estimated by the CPES were adjusted to one-year utilization rates using the reported ratio of any service one-year utilization to any lifetime utilization (approximately 77.3%). The estimated utilization rates are summarized in Table 4.4.

Given the limitations in available literature, an average frequency of service among individuals accessing treatment services for their ED was calculated across multiple sources:

- Striegel-Moore et al. (2008)<sup>95</sup> estimated past 12-month health resource use based on a sample of US adults who received treatment for a diagnosed ED between 2002 and 2004 through a large healthcare organization plan. Based on the excess utilization reported by the authors, which was estimated at 4.2 visits to mental health practitioners and 1.83 visits to primary care providers.<sup>96</sup>
- Ling et al. (2017)<sup>97</sup> estimated that people accessing treatment for BED would see a primary care provider an average of 2.6 times per annum due to their ED. The sample comprised 1,720 respondents to the US National Health and Wellness Survey conducted in 2013.

The incremental service cost of primary care provider service use was found to be \$95 per visit in 2018-19 based on CMS code 99214, while the average cost of a mental health practitioner presentation for psychotherapy was found to be \$88 based on CMS code 90834<sup>98</sup>.

The average cost per person was estimated to be \$547, comprising of \$377 for mental health visits<sup>99</sup> and \$170 for primary care provider visits (Table 4.4).

Table 4.4: Primary and outpatient health service utilization rates, one year

Service	Proportion of people accessing service	Number of visits past 12 months*	Average unit cost (\$)	Total cost per person with an ED (\$)
Mental health practitioner	12.0	35.8	88	377
Primary care provider	59.8	3.0	95	170
<b>Total</b>				<b>547</b>

Source: Deloitte Access Economics modelling. CPES (2003), Swanson et al. (2011), Striegel-Moore et al. (2008), Ling et al. (2017), CMS (2020), Ballard and Crane (2014).

\* data were derived based on average utilization rates from CPES to ensure that the average number of visits was equal to the

<sup>94</sup> Alegria, M. (2016). Collaborative Psychological Epidemiological Surveys (CPES). Retrieved from <<https://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240>>.

<sup>95</sup> Striegel-Moore, R. H., DeBar, L., Wilson, G. T., Dickerson, J., Rosselli, F., Perrin, N., ... & Kraemer, H. C. (2008). Health services use in eating disorders. *Psychological medicine*, 38(10), 1465-1474.

<sup>96</sup> Assuming the CPES rates are generalizable to the study population used by Striegel-Moore et al. (2008), the average excess utilization rates reported by the authors imply that individuals accessing treatment would see a psychiatrist an average of 35.8 times per annum, and a primary care provider an average of 3.1 times per annum.

<sup>97</sup> Ling, Y. L., Rascati, K. L., & Pawaskar, M. (2017). Direct and indirect costs among patients with binge-eating disorder in the United States. *International Journal of Eating Disorders*, 50(5), 523-532.

<sup>98</sup> CMS (2020). Physician Fee Schedule. Retrieved from <<https://www.cms.gov/apps/physician-fee-schedule/search>>.

<sup>99</sup> For the purposes of this report, mental health visits were assumed to capture the costs associated with visits for an ED to psychiatrists, psychologists and social workers.

underlying incremental difference within Striegel-Moore et al. (2008) and Ling et al. (2017). Note: components may not sum to totals due to rounding.

### Summary of primary and outpatient healthcare

Overall primary and outpatient healthcare costs were calculated by multiplying the estimated average cost per person with an ED by the corresponding number of prevalent cases estimated in chapter 3.

As summarized in Table 4.5, it was calculated that the largest primary and outpatient healthcare costs were associated with OSFED (\$1.3 billion), followed by BED (\$1.1 billion). The primary and outpatient healthcare costs due to EDs were calculated to total \$3.4 billion in 2018-19.

Table 4.5: Breakdown of annual primary and outpatient care costs by condition, 2018-19

Condition	Average cost per person with an ED (\$)	Total cost (\$ million)
AN	841	343.0
BN	1,031	641.3
BED	547	1,112.2
OSFED	547	1,322.3
<b>Total / weighted average</b>	<b>624</b>	<b>3,418.8</b>

Source: Deloitte Access Economics modelling, Guroo (2019), Fairhealth (2019), Ballard and Crane (2014), CPES (2003), Striegel-Moore et al. (2008), Ling et al. (2017), Swanson et al. (2011). Note: components may not sum to totals due to rounding.

#### 4.1.4 Residential care

Residential care services refer to formal, around-the-clock care settings, primarily focused on providing psychological treatment to medically-stabilized patients (Fisher et al., 2020).<sup>100</sup>

Based on data provided by the Residential Eating Disorders Consortium (2019) members survey,<sup>101</sup> there are approximately 1,473 adult beds and 601 adolescent beds. It was assumed that each bed would be occupied for approximately 85% of the full year. These figures were multiplied by the number of days in a year (365) to get the total number of days of residential treatment supplied for individuals with an ED. This approach yielded an estimate of 456,998 days of adult treatment and 186,460 days of adolescent treatment delivered. When the total days of care are divided by the average length of stay reported in the REDC member survey (approximately 31.3 days for adults and 40.6 days for adolescents), it is possible that almost 19,200 people received care from residential care services in 2018-19. However, this number may be lower as people could be admitted more than once in the same year.

Based on a literature review (search strings provided in A.2), the most recently published estimate of the average cost of treatment per day was provided by Frisch et al. (2006)<sup>102</sup>. Based on a national study of 22 residential ED treatment programs, the authors reported an average cost per day of \$956 for residential care in the US in 2006. In the absence of a more recent representative estimate, this figure was adjusted for health inflation<sup>103</sup> to estimate the daily cost of residential care for 2018-19 (\$1,237). This average daily cost of residential treatment was multiplied by the

<sup>100</sup> Fisher, M., Henretty, J. R., Cox, S. A., Feinstein, R., Fornari, V., Moskowitz, L., ... & Fishbein, J. (2020). Demographics and Outcomes of Patients With Eating Disorders Treated in Residential Care. *Frontiers in Psychology*, 10, 2985.

<sup>101</sup> Unpublished data.

<sup>102</sup> Frisch, M. J., Herzog, D. B., & Franko, D. L. (2006). Residential treatment for eating disorders. *International Journal of Eating Disorders*, 39(5), 434-442.

<sup>103</sup> Centers for Medicare and Medicaid Services (CMS) (2019). Personal Health Care (PHC) indices – overall. Retrieved from <<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/Tables.zip>>.

number of days of treatment supplied, yielding an estimated total cost of residential care of \$565.6 million for adults and \$230.8 million for adolescents.

This total cost was then distributed on the basis of the number of individuals receiving treatment in each age group, according to condition, and adjusted for length of stay, estimated by REDC (2019).<sup>104</sup> These results are summarized in Table 4.6 and Table 4.7.

Table 4.6: Cost of residential care in 2018-19

Parameter	Estimate
Number of adolescent beds utilized per annum	601
Number of adult beds utilized per annum	1,473
Occupancy rate (%)	85
Average cost per day (\$)	1,237
<b>Total cost (\$ millions)</b>	<b>796.3</b>

Source: Deloitte Access Economics analysis based on Fisher et al. (2020), Frisch et al. (2006). Note: components may not multiply to totals due to rounding.

**Overall, it was estimated that residential care costs due to EDs totaled \$796.3 million in 2019.** The largest share of these costs was borne by individuals with AN (\$565.1 million). Table 4.7 also reports the average annual cost of residential care across all individuals with a specific ED diagnosis. An individual with AN faced the highest cost of residential care, with each prevalent case incurring an average cost of \$1,385. This was followed by average costs of \$206 for individuals with BN, \$29 for individuals with OSFED, and \$16 for individuals with BED. The weighted average cost across all EDs was estimated to be \$145 per person.

Table 4.7: Breakdown of residential care costs by condition, 2018-19

Condition	Total cost (\$ million)	Average annual cost per person with an ED (\$)
AN	565.1	1,385
BN	128.0	206
BED	32.2	16
OSFED	70.9	29
<b>Total / weighted average</b>	<b>796.3</b>	<b>145</b>

Source: Deloitte Access Economics analysis based on Fisher et al. (2020), Frisch et al. (2006). Note: components may not sum to totals due to rounding.

#### 4.1.5 Pharmaceuticals

While pharmaceuticals are not a first line treatment for all people with EDs, they are still sometimes used as an adjunct to other therapy. Medications used in the treatment of EDs mostly fall under the psychotherapeutic class of drugs. For BED, listed medications include Lisdexamfetamine, Topiramate, and second-generation antidepressants<sup>105</sup>.

<sup>104</sup> Unpublished data.

<sup>105</sup> AHRQ (2016). *Treating Binge-eating Disorder*. Retrieved from <<https://effectivehealthcare.ahrq.gov/products/binge-eating/consumer>>.

Expenditure on psychotherapy drugs was informed based on MEPS and literature on the utilization of psychotherapeutic medications. The latter was due to the relatively small sample size in MEPS for pharmaceutical expenditure (less than 10 people in 2012<sup>106</sup>).

The average expenditure on psychotherapeutic medications for people with EDs in 2012 was approximately \$49.14 across the year, which was inflated using health inflation<sup>107</sup> to estimate that the average expenditure on psychotherapeutic drugs was \$54.71 in 2018-19.

A scan of the literature led to medication utilization rates based on Coffino et al. (2019)<sup>108</sup> as it was the most representative US data source.<sup>109</sup> Using this source, it was assumed that 17.9% of individuals with BED and OSFED, 7.8% of individuals with AN, and 18.4% of individuals with BN used pharmaceuticals for their condition. These rates were multiplied by the prevalence of these conditions, while the average annual cost of psychotherapeutic medications was derived based on MEPS.

Table 4.8: Pharmaceutical costs due to EDs by condition, 2018-19

Condition	Proportion of people using pharmaceuticals (%)	Average annual costs of pharmaceuticals per person with an ED (\$)	Total annual cost of pharmaceuticals (\$ million)
AN	7.8	4	1.7
BN	18.4	10	6.3
BED	17.9	10	19.9
OSFED	17.9	10	23.7
<b>Total / weighted average</b>		<b>9</b>	<b>51.6</b>

Source: Deloitte Access Economics analysis based on MEPS (2012), Coffino et al. (2019). Note: components may not sum to totals due to rounding.

**Overall, it was estimated that \$51.6 million was spent on psychotherapeutic medications for the treatment of EDs in 2018-19.**<sup>110</sup>

#### 4.1.6 Other health system costs

Given the limitations associated with available data, a number of health system costs were conservatively excluded from the analysis included in this report. Individuals with an ED are likely to access health professionals such as dietitians, pediatricians, internists, and adolescent medicine

<sup>106</sup> The 2012 MEPS data were the latest available that provided sufficient variables to estimate pharmaceutical for specific indications, where that indication did not rely on EDs being recorded as the primary condition for each individual. That is, the related ICD-9 code was also provided for each medication event.

<sup>107</sup> Centers for Medicare and Medicaid Services (CMS) (2019). Personal Health Care (PHC) indices – overall. Retrieved from <<http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/Tables.zip>>.

<sup>108</sup> Coffino, J. A., Udo, T., & Grilo, C. M. (2019). Rates of help-seeking in US adults with lifetime DSM-5 eating disorders: prevalence across diagnoses and differences by sex and ethnicity/race. In *Mayo Clinic Proceedings* (Vol. 94, No. 8, pp. 1415-1426). Elsevier.

<sup>109</sup> Other results from the literature suggested that: (1) 72% of people with BED in Canada reported any medication use; (2) people covered by the Department of Veterans Affairs insurance scheme with an ED may fill upwards of 40 pharmacy scripts, on average, following diagnosis, with the unadjusted costs up to \$8,500 to \$11,000 higher compared to controls without EDs; (3) Striegel Moore et al. (2008) reported that individuals with an ED used addiction medications and anxiolytics to manage their condition, with the highest utilization rates recorded for individuals in the 35 to 55 year old age group; and (4) While data were available on the anxiolytics, antidepressants and addiction medications associated with psychotherapy for individuals with an ED, there was insufficient information to support attributing other medications in the treatment of EDs (such as medications and supplements that may be used to help replace the effects of a changed diet).

<sup>110</sup> Applying the average costs of psychotherapy treatment and the findings from Coffino et al. (2019) more broadly to AN and BN, it was estimated that more than \$58 million was spent on psychotherapy medications for the treatment of EDs in 2018-19. As noted, pharmacy related costs for AN and BN have not been reported separately as these are included within the additional costs reported by Samnaliev et al. (2014).

specialists, however there was no representative data located that estimated the usage of these services among individuals with BED or OSFED in the US.

Haas (2012)<sup>111</sup> estimated the inpatient costs of EDs based on a cohort of cases in German hospitals. The authors found that dietitian costs represented an average of approximately 6.4% of total inpatient costs across individuals with AN, BN and obesity due to ED. If it is assumed that this proportion of dietitian costs to total inpatient hospital costs applies across all EDs and in the US, the **magnitude of costs for dietitians and nutritionists may be around \$47.6 million**. Alternatively, dated evidence from the US has shown that approximately 18.6% of women with EDs have sought nutrition counseling because of their ED (not limited to within the previous year): participants also reported an average of 16.7 sessions.<sup>112</sup> If these help-seeking rates apply within a year, and all sessions were contained in this year, **nutrition therapy costs may be as much as \$570 million** in the US today.<sup>113</sup> However, further research is required to understand current utilization of these services today.

These costs have been conservatively excluded from the estimates provided by this report, in the absence of recent representative US data.

Similarly, the cost of diagnostic testing for EDs was excluded due to a lack of available information. However, this is likely to have a small effect on the magnitude of overall cost estimated, since individuals with EDs are most likely to receive diagnosis through presentation to a trained mental health professional, or primary care provider.

#### **4.1.7 Medical research**

In addition to resources that are used to directly treat people with EDs, it is also relevant to include medical research on EDs as a cost of the condition. Medical research costs are sometimes excluded from cost-of-illness studies; however, medical research expenditure would not be incurred if the condition did not exist. It is noted that medical research costs are often excluded where these costs may be recovered in average charges for services (which may be the case for hospital-funded research, for example) to avoid double counting, or where the purpose of the analysis may be to estimate the value of research in reducing the cost of a condition. Importantly, medical research is included in this analysis (where double counting does not occur) since these costs would not be incurred in the absence of EDs and could instead be reallocated to other research purposes.

A large amount of medical research into EDs in the US is funded by the National Institute of Health, the lead federal agency for research on health disorders. The National Institute of Health published categorical estimates by disease and condition group of the annual support provided for research conducted.<sup>114</sup>

In addition to this component of \$44.0 million, there are also the following components:

- The Federal Substance Use and Mental Health Services Administration awarded a \$3.75 million five year grant for the first Center of Excellence for Eating Disorders to offer provider training.

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<sup>111</sup> Haas, L., Stargardt, T., Schreyoegg, J., Schlösser, R., Hofmann, T., Danzer, G., & Klapp, B. F. (2012). Introduction of DRG-based reimbursement in inpatient psychosomatics—an examination of cost homogeneity and cost predictors in the treatment of patients with eating disorders. *Journal of psychosomatic research*, 73(5), 383-390.

<sup>112</sup> Yager, J., Landsverk, J., & Edelstein, C. K. (1989). Help seeking and satisfaction with care in 641 women with eating disorders. I. Patterns of utilization, attributed change, and perceived efficacy of treatment. *The Journal of nervous and mental disease*, 177(10), 632-637.

<sup>113</sup> To estimate this possible range, 18.6% was multiplied by total one-year prevalence of EDs in the US in 2018-19, which was then multiplied by the average number of sessions (16.7) and the average cost of medical nutrition therapy (\$38.25 for the first session and \$33.20 for each session thereafter, based on CMS' HCPCS codes 97802 and 97803; these represent the non-facility prices for 2019). It is likely that help-seeking rates within the last year are lower and it is not clear whether these rates would apply today.

<sup>114</sup> National Institute of Health (NIH). (2020). Estimates of funding for various research, condition and disease categories (RCDC). Retrieved from <[https://report.nih.gov/categorical\\_spending.aspx](https://report.nih.gov/categorical_spending.aspx)>.



- Research funding within the Department of Defense’s Peer Reviewed Medical Research Program for 2017 through 2019 provided approximately \$5 million in funding per year.<sup>115</sup>

Aggregating these components provided a total **estimated financial value of medical research for EDs in 2018-19 of \$49.8 million (or \$9 per person with an ED in 2018-19)**. While this is a conservative estimate,<sup>116</sup> this funding amount is low relative to other conditions, particularly after accounting for the wellbeing loss from EDs. For example, 2017 categorical grants data published by the NIH indicates funding amounts of \$239 per individual with Alzheimer’s disease, \$109 per individual with autism, and \$69 per individual with schizophrenia.<sup>117</sup>

Importantly, the relatively low funding per person with an ED compared to other mental health conditions indicates that there may be an opportunity to improve research funding – in line with other mental health conditions – so that outcomes for EDs may be improved and the overall burden of EDs on society may be reduced.

Table 4.9: Medical research (NIH) expenditure for EDs, 2018-19

Component	Total cost (\$ million)
Medical research	49.8

Source: NIH (2020).

#### 4.1.8 Summary of health system costs

**The total health system costs associated with EDs in the US were estimated at \$4.6 billion in 2018-19.** OSFED accounted for the largest share of costs (\$1.5 billion), followed by BED (\$1.2 billion), AN (\$1.1 billion), and BN (\$0.8 billion). The estimated average cost per person was highest for individuals with AN (\$2,615), followed by those with BN (\$1,335).

Table 4.10: Health system costs by condition for EDs, 2018-19

Category	Average annual health system cost per person with an ED (\$)	Total annual costs (\$ million)
AN	2,615	1,067.1
BN	1,335	830.3
BED	590	1,199.3
OSFED	603	1,458.8
<b>Total / weighted average</b>	<b>831</b>	<b>4,555.4</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

The proportion of health system costs incurred by each payer were derived separately for hospitalizations and emergency department, and other health system costs.

<sup>115</sup> Austin, S. B., Hutcheson, R., Wickramatilake-Templeman, S., & Velasquez, K. (2019). The second wave of public policy advocacy for eating disorders: charting the course to maximize population impact. *Psychiatric Clinics*, 42(2), 319-336.

<sup>116</sup> This estimated cost of medical research is conservative as it does not capture broader research related to mental health issues which may in part be attributable to EDs. Further research funding is also likely to be made by private companies and research institutions such as universities and hospitals. These components are conservatively excluded from the scope of this report, due to lack of data.

<sup>117</sup> Austin, S. B., Hutcheson, R., Wickramatilake-Templeman, S., & Velasquez, K. (2019). The second wave of public policy advocacy for eating disorders: charting the course to maximize population impact. *Psychiatric Clinics*, 42(2), 319-336.

To inform the distribution of hospitalization and emergency department costs by payer, the most representative source was found to be AHRQ (2016)<sup>118</sup>, which estimated the costs of hospitalizations due to EDs across all recorded hospitalizations in the US. Other health system costs were broken down by payer using 2019 National Health Expenditure Accounts data published by the CMS.<sup>119</sup> These sources are still subject to a number of limitations and are unlikely to perfectly represent individuals with EDs, who tend to be younger and thus often ineligible for Medicare.

Table 4.11: Estimated distribution of health system costs by source of funds (%), 2018-19

Payer	Hospitalizations and emergency department costs	All other health system costs
Government	33.8%	39.4%
Private health insurance	61.7%	41.8%
Out-of-pocket	2.2%	10.5%
Other	2.4%	8.3%

Source: Deloitte Access Economics analysis based on AHRQ (2020), CMS (2019). Note: components may not sum to totals due to rounding.

Table 4.12 shows health system costs associated with EDs by type of cost and by payer.

Table 4.12: Health system costs of EDs by type of cost and source of funds, 2018-19, \$ millions

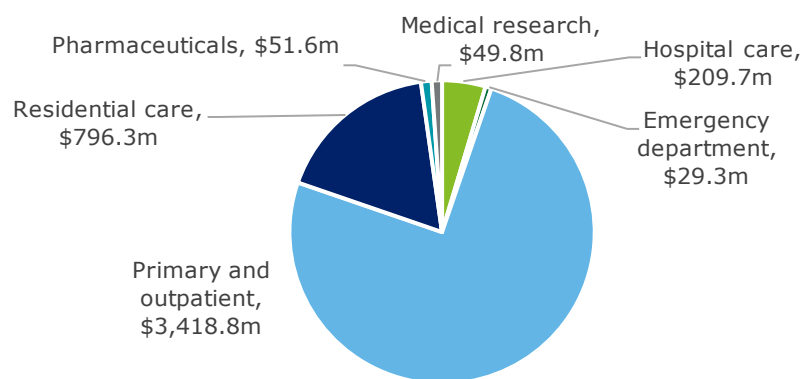
Component	AN	BN	BED	OSFED	Total
Individuals	69.9	68.7	103.4	121.5	363.5
Family/friends	31.2	15.1	21.6	30.6	98.5
Government	412.8	324.7	471.7	573.7	1,782.9
Society/other	553.2	421.8	602.6	733.0	2,310.6
<b>Total</b>	<b>1,067.1</b>	<b>830.3</b>	<b>1,199.3</b>	<b>1,458.8</b>	<b>4,555.4</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

<sup>118</sup> Agency for Healthcare Research and Quality (AHRQ) (2016). Healthcare cost and utilization project. Retrieved from <<https://hcupnet.ahrq.gov/>> .

<sup>119</sup> CMS (2019). National Health Expenditure Accounts: Historical Data. Retrieved from <<https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical>>

Chart 4.1: Costs of EDs by type of cost, 2018-19



Source: Deloitte Access Economics analysis.

## 4.2 Productivity costs

EDs have a negative effect upon an individual's ability to function, with respect to their engagement in work and their relationships with families. Adopting a societal perspective there are significant indirect costs that are a result of absenteeism, presenteeism, disability and premature death. A lost lifetime earnings approach was employed in calculating the overall productivity losses as a result of an ED.<sup>120</sup> This human capital approach to valuing productivity costs is in line with the most commonly used best practice cost-of-illness methodologies and multiplies an individual's probability of employment by their forgone wage earnings to measure the value of lost production.<sup>121</sup>

### 4.2.1 Reduced workforce participation

An ED can reduce workforce participation, as people are either unable to participate in the workforce due to their condition or choose not to participate. This can lead to significant productivity losses in the form of lost wages and other costs to the individual, such as reduced social engagement.

Samnaliev et al. (2014)<sup>122</sup> analyzed five years of historical data from MEPS to estimate the difference in annual healthcare costs, employment status and earned income for those individuals with EDs versus those without an ED. The authors published an odds ratio of being employed for those with an ED compared to those without, which was 0.67. The odds ratio was multiplied by the employment rates in the general working age population (approximately 75% of people in the general population are employed), indicating that people with EDs were therefore about **10.8% less likely to be employed.**<sup>123</sup>

<sup>120</sup> Average earnings data and employment rates was obtained for the general US population in 2020 based on publicly-available administrative data.

US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>

US Bureau of Labor Statistics (BLS). (2020). Economic News Release: Employment Situation. Retrieved from <<https://www.bls.gov/news.release/empsit.toc.htm>>.

<sup>121</sup> Segel, J. E. (2006). Cost-of-illness studies—a primer. RTI-UNC Center of Excellence in Health Promotion Economics, 2006, 1-39.

<sup>122</sup> Samnaliev, M., Noh, H. L., Sonnevill, K. R., & Austin, S. B. (2014). The economic burden of eating disorders and related mental health comorbidities: An exploratory analysis using the US Medical Expenditures Panel Survey. Preventive medicine reports, 2, 32-34.

<sup>123</sup> Samnaliev, M., Noh, H. L., Sonnevill, K. R., & Austin, S. B. (2014). The economic burden of eating disorders and related mental health comorbidities: An exploratory analysis using the US Medical Expenditures Panel Survey. Preventive medicine reports, 2, 32-34.

The CPES (2003)<sup>124</sup> asked respondents whether they had worked for pay or profit in the last week. Results from the CPES (2003) found that individuals with **AN or BN were 29.3% less likely to be employed** compared to the general population,<sup>125</sup> while people with **BED were 4.8% less likely to be employed**.<sup>126</sup>

For the purpose of this report, it was assumed that the employment impact for AN and BN was the average of Samnaliev et al. (2014) and CPES (**20.1% less likely to be employed**), while the employment impact for BED and OSFED was based on the results for BED from CPES (**4.8% less likely to be employed**).

To estimate the costs of reduced employment associated with EDs, the relative reduction in employment was multiplied by the US general population employment rates<sup>127</sup> and average weekly earnings (AWE) by age and gender<sup>128</sup>. Earnings were adjusted to incorporate employment benefits, using the ratio of wages and salaries to total employee compensation<sup>129</sup>. **Reduced employment associated with EDs was estimated to cost \$15.2 billion in 2018-19, or \$2,782 per person living with an ED.**

Table 4.13: Reduced workforce participation by condition, 2018-19

Condition	Data source	Reduction in participation (%)	Total cost (\$m)
AN	Samnaliev et al. (2014), CPES (2003)	20.1%	3,035.2
BN	Samnaliev et al. (2014), CPES (2003)	20.1%	4,790.0
BED	CPES (2003)	4.8%	3,408.8
OSFED	CPES (2003)	4.8%	4,012.3
<b>Total</b>			<b>15,246.2</b>

Source: As noted in table. Note: components may not sum to totals due to rounding.

#### 4.2.2 Absenteeism

Absenteeism is defined as being temporarily absent from paid employment due to an ED. Absenteeism is measured by the average number of days per year that an employee takes off work as a result of their ED.

The most representative source for the US was found to be the CPES (2003). A nationally representative sample of survey respondents were asked to answer the number of days in the past year they were unable to work due to eating problems. Based on these data, it was estimated that individuals with AN or BN were absent from work for an additional 27.3 days due to problems with eating or weight in the last year. Similarly, people with BED were absent from work for an additional 4.2 days due to problems with eating or weight in the last year. In the absence of

<sup>124</sup> Alegria et al. (2016), Collaborative Psychiatric Surveys (CPES), 2001-2003. Retrieved from <<https://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240>>.

<sup>125</sup> Only 2 cases of AN were reported in the CPES data. Consequently, the data were pooled with BN to provide more robust results across both conditions.

<sup>126</sup> Data were adjusted for differences in age and gender.

<sup>127</sup> US Bureau of Labor Statistics (BLS). (2020). Economic News Release: Employment Situation. Retrieved from <<https://www.bls.gov/news.release/empsit.toc.htm>>

<sup>128</sup> US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>.

<sup>129</sup> US Bureau of Labor Statistics (BLS). (2019). Employer costs for employee compensation – June 2019. Retrieved from <[https://www.bls.gov/news.release/archives/ecec\\_09172019.pdf](https://www.bls.gov/news.release/archives/ecec_09172019.pdf)>.

sufficient data to identify absenteeism for OSFED, it was assumed that the impacts would be the same as BED.<sup>130</sup>

To estimate the costs of absenteeism associated with EDs, the average additional days absent from work was then multiplied by the US general population employment rates<sup>131</sup> and AWE by age and gender<sup>132</sup>. Earnings were adjusted to incorporate employment benefits, using the ratio of wages and salaries to total employee compensation<sup>133</sup>. Additional costs were also included for management time associated with the absence from work.<sup>134</sup> **Absenteeism associated with EDs was estimated to cost \$6.4 billion in 2018-19, or \$1,166 per person living with EDs.**

Table 4.14: Workforce absenteeism by condition, 2018-19

Condition	Source	Mean days absent	Total cost (\$m)
AN	CPES (2003)	27.3	1,547.2
BN	CPES (2003)	27.3	1,388.8
BED	CPES (2003)	4.2	1,583.8
OSFED	CPES (2003)	4.2	1,869.9
<b>Total</b>			<b>6,389.7</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

#### 4.2.3 Presenteeism

Presenteeism refers to reduced productivity while an employee is at work but suffering from an ED. Presenteeism is measured as the average number of hours per day that an employee loses to reduced performance or impaired function as the result of their condition. Presenteeism is not as easily measured as absenteeism, but it has the potential to incur significant costs to employers by reducing the quality and efficiency of work produced by employees. Ultimately, while borne by employers in the initial instance, most of these costs are later passed on to the employer's labor force or society in general.

The inclusion of indirect costs such as presenteeism is an important component of cost-of-illness methodology, as indicated by best practice guidelines such as Segel et al. (2006)<sup>135</sup>.

Pawaskar et al. (2017)<sup>136</sup> estimated the impact of BED on functional impairments on work productivity in a nationally representative sample of US adults through the National Health and

<sup>130</sup> Other studies have estimated that absenteeism impacts in people with EDs can be up to 46% higher compared to people without EDs (e.g. Ling et al., 2017). However, in analyses adjusted for confounding factors, the absenteeism impact was substantially lower (Pawaskar et al., 2017).

Ling, Y. L., Rascati, K. L., & Pawaskar, M. (2017). Direct and indirect costs among patients with binge-eating disorder in the United States. *International Journal of Eating Disorders*, 50(5), 523-532.

Pawaskar, M., Witt, E. A., Supina, D., Herman, B. K., & Wadden, T. A. (2017). Impact of binge-eating disorder on functional impairment and work productivity in an adult community sample in the United States. *International journal of clinical practice*, 71(7), e12970.

<sup>131</sup> US Bureau of Labor Statistics (BLS). (2020). Economic News Release: Employment Situation. Retrieved from <<https://www.bls.gov/news.release/empsit.toc.htm>>

<sup>132</sup> US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>.

<sup>133</sup> US Bureau of Labor Statistics (BLS). (2019). Employer costs for employee compensation – June 2019. Retrieved from <[https://www.bls.gov/news.release/archives/eccec\\_09172019.pdf](https://www.bls.gov/news.release/archives/eccec_09172019.pdf)>.

<sup>134</sup> On average, the costs of manager time increase the cost of absenteeism by 40% compared to AWE alone.

<sup>135</sup> Segel, J. E. (2006). Cost-of-illness studies—a primer. RTI-UNC Center of Excellence in Health Promotion Economics, 2006, 1-39.

<sup>136</sup> Pawaskar, M., Witt, E. A., Supina, D., Herman, B. K., & Wadden, T. A. (2017). Impact of binge-eating disorder on functional impairment and work productivity in an adult community sample in the United States. *International journal of clinical practice*, 71(7), e12970.

Wellness Survey. In analyses adjusted for confounding factors, the authors reported that BED respondents had greater levels of presenteeism compared to respondents without BED, indicated by a **10.2% difference in presenteeism**.

In the absence of other US presenteeism sources, it was assumed that the level of presenteeism in people with AN, BN and OSFED was the same as for BED (10.2%). There is some evidence to suggest that this result may be conservative. For example, data from CPES indicates that the average presenteeism impact in people with BED may be as high as 22.7%, with comparable results for AN and BN where the pooled presenteeism impact was 22.8%. While CPES provides an indication of the effect size, it could not be used in the analysis as the question asks respondents to think about the month in the last year where they had the most problems with their weight or eating, rather than asking for an average over the last month or the last year.<sup>137</sup> In contrast, a study on the impacts of binge-eating found that people who binge-eat four or more times per week had excess work impairment of 2.9% while people who binge-eat fewer than four times per week had excess work impairment of 2.2%.<sup>138</sup> While the study was able to control for possible confounding factors such as weight, depression, alcohol use and others, it did not include a formal diagnosis of BED, and so it has not been used in the modelling in this report.

To estimate the costs of presenteeism associated with EDs the average additional reduction in productivity while at work was then multiplied by the US general population employment rates<sup>139</sup> and AWE by age and gender<sup>140</sup>. Earnings were adjusted to incorporate employment benefits, using the ratio of wages and salaries to total employee compensation<sup>141</sup>. **Presenteeism associated with EDs was estimated to cost \$18.2 billion in 2018-19, or \$3,324 per person living with EDs.**

Table 4.15: Workforce presenteeism by condition, 2018-19

Condition	Source	Presenteeism impact	Total cost (\$m)
AN	Pawaskar et al. (2017)	10.2%	1,417.5
BN	Pawaskar et al. (2017)	10.2%	1,942.4
BED	Pawaskar et al. (2017)	10.2%	6,825.4
OSFED	Pawaskar et al. (2017)	10.2%	8,033.7
<b>Total</b>			<b>18,219.0</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

#### 4.2.4 Premature mortality

As noted in chapter 2, there were an estimated 10,200 deaths due to EDs in the US in 2018-19. Based on the age-gender distribution of these deaths, and incorporating employment rates and estimates of average lifetime earnings for these groups, the value of lost earnings due to mortality among those who would otherwise have been employed was estimated to be \$857,336 per death.

<sup>137</sup> The estimated presenteeism impact is also comparable to results reported by Deloitte Access Economics (2012), who conducted a survey of Australians with EDs, and estimated the reduction in productivity due to presenteeism to average 20.4% across all conditions.

<sup>138</sup> Bedrosian, R. C., Striegel, R. H., Wang, C., & Schwartz, S. (2012). Association of binge eating with work productivity impairment, adjusted for other health risk factors. *Journal of occupational and environmental medicine*, 54(4), 385-393.

<sup>139</sup> US Bureau of Labor Statistics (BLS). (2020). Economic News Release: Employment Situation. Retrieved from <<https://www.bls.gov/news.release/empsit.toc.htm>>

<sup>140</sup> US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>.

<sup>141</sup> US Bureau of Labor Statistics (BLS). (2019). Employer costs for employee compensation – June 2019. Retrieved from <[https://www.bls.gov/news.release/archives/ecec\\_09172019.pdf](https://www.bls.gov/news.release/archives/ecec_09172019.pdf)>.

The estimated **annual cost due to lost productivity due to premature death associated with EDs was calculated to total \$8.8 billion in 2018-19.**

The predominant prevalence of EDs for those in young age groups, where potential lifetime earning is significant, explains the large magnitude of these costs.

Premature death also leads to additional search and hiring costs for replacement workers. These were estimated as the number of people with EDs (by age and gender) who die prematurely, multiplied by the chance of being employed (if they did not die), multiplied by the search and hiring cost brought forward three years<sup>142</sup>. The search and hiring cost was estimated as 26 weeks at AWE<sup>143</sup> and the three years brought forward was assumed to reflect average staff turnover rates in the US. Earnings were adjusted to incorporate employment benefits, using the ratio of wages and salaries to total employee compensation<sup>144</sup>.

In 2018-19, the **additional search and hiring costs were estimated at \$14.1 million**, very small compared to the loss of future income streams, so the **total costs of premature mortality associated with EDs remained (rounded) at \$8.8 billion in 2018-19, or \$1,602 per person with EDs**. The per person costs were substantially higher in AN, and the total costs were also higher in AN (32% of premature mortality costs, and 7% of total prevalence) reflecting the much greater impact of AN on mortality rates.

Table 4.16: Productivity losses from premature mortality by condition, 2018-19

Condition	Number of deaths	Total cost (\$m)
AN	2,700	2,770.4
BN	1,000	826.2
BED	3,100	2,420.3
OSFED	3,400	2,762.4
<b>Total</b>	<b>10,200</b>	<b>8,779.3</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

#### 4.2.5 Summary of productivity costs

Productivity losses for people with EDs were estimated to be \$48.6 billion. Of the productivity losses, reduced employment accounted for \$15.2 billion (31%), and premature mortality, absenteeism and presenteeism accounted for \$8.8 billion (18%), \$6.4 billion (13%) and \$18.2 billion (37%), respectively (Chart 4.2). Of the total productivity costs, 37.9% is borne by individuals, 28.6% is borne by government and 33.6% is borne by employers as shown in Chart 4.2.

The magnitude of these costs is large, and highly impactful for people with EDs. On average, productivity losses were estimated to be \$8,874 per person with EDs. These costs were most severe for individuals with AN (\$21,496 per person), followed by those with BN (\$14,388 per person) and BED (\$7,002 per person). The results are shown in Table 4.17.

<sup>142</sup> US Bureau of Labor Statistics (BLS) (2018). National Occupational Employment and Wage Estimates United States. Retrieved from <[https://www.bls.gov/oes/current/oes\\_nat.htm#11-0000](https://www.bls.gov/oes/current/oes_nat.htm#11-0000)>.

SHRM (2014) reported that there was 1.2 hours of manager time required per temporary absence. Society for Human Resource Management (SHRM). (2014). Total financial impact of employee absences in the US. Retrieved from <[https://www.shrm.org/hr-today/news/hr-magazine/documents/kronos\\_us\\_executive\\_summary\\_final.pdf](https://www.shrm.org/hr-today/news/hr-magazine/documents/kronos_us_executive_summary_final.pdf)>.

On-costs as a proportion of AWE were assumed at 18.0% based on Deloitte Access Economics (2012).

<sup>143</sup> US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>.

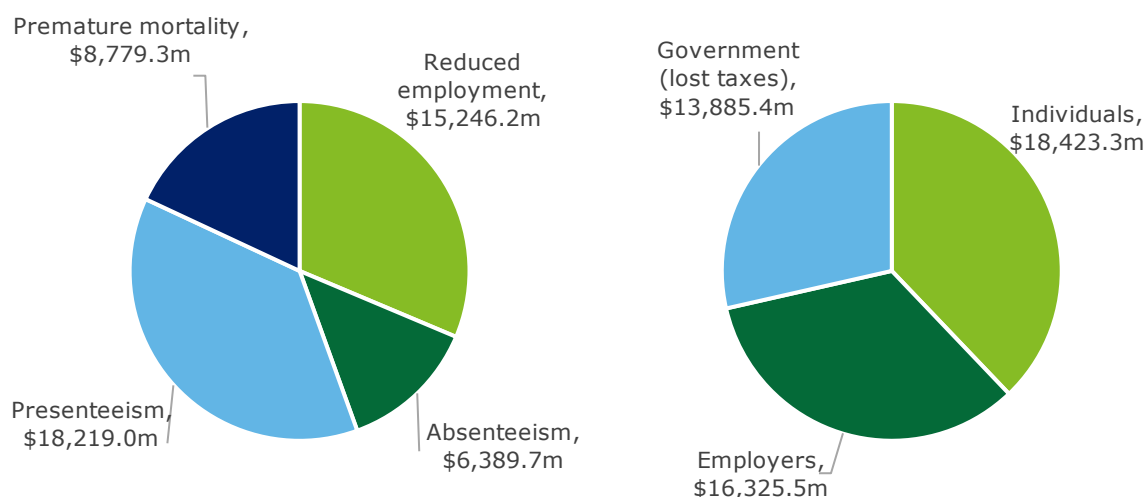
<sup>144</sup> US Bureau of Labor Statistics (BLS). (2019). Employer costs for employee compensation – June 2019. Retrieved from <[https://www.bls.gov/news.release/archives/ecce\\_09172019.pdf](https://www.bls.gov/news.release/archives/ecce_09172019.pdf)>.

Table 4.17: Productivity costs associated with EDs in 2018-19

ED	Reduced employment (\$m)	Absenteeism (\$m)	Presenteeism (\$m)	Premature mortality (\$m)	Total (\$m)	Cost per person with an ED (\$)
AN	3,035.2	1,547.2	1,417.5	2,770.4	8,770.3	21,496
BN	4,790.0	1,388.8	1,942.4	826.2	8,947.3	14,388
BED	3,408.8	1,583.8	6,825.4	2,420.3	14,238.4	7,002
OSFED	4,012.3	1,869.9	8,033.7	2,762.4	16,678.3	6,899
<b>Total</b>	<b>15,246.2</b>	<b>6,389.7</b>	<b>18,219.0</b>	<b>8,779.3</b>	<b>48,634.3</b>	<b>8,874</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

Chart 4.2: Productivity costs by component (left) and payer (right)



Source: Deloitte Access Economics analysis.

### 4.3 Caregiver costs

Caregivers provide support to individuals in need of care. A caregiver provides this service free of charge and does so outside of the formal care sector. A caregiver will typically be a family member or friend of the person receiving care, and usually lives in the same household as the recipient of care. People can receive informal care from more than one person.

While caregivers are not paid for providing this care, informal care is not free in an economic sense. Time spent caring involves forfeiting time that could be spent on paid work or undertaking leisure time activities.

As such, informal care can be valued as the opportunity cost associated with the loss of economic resources (labor) and the loss in leisure time valued by the caregiver. To estimate the dollar value of informal care, the opportunity cost method measures the formal sector productivity losses associated with caring, as time devoted to caring responsibilities is time that cannot be spent in the paid workforce.

To estimate the costs of informal care for Americans with an ED, it was necessary to estimate the proportion of people receiving support from a caregiver and also the number of hours of care provided. Data were not clearly defined in a US based population, however, so estimates around the duration of care are derived from other generalizable populations.



It is important to note that irrespective of the type of ED, the demands of care are different, for example, depending on the time lapse between when symptoms present and a clinical diagnosis is made.

A literature review was conducted to identify studies that measure informal care contact hours provided to people with an ED (search strings provided in A.2). Types of care provided by an informal caregiver include medical support (e.g. attendance with and transport to appointments, plus oversight and coordination of health services), food provision and monitoring, personal and household services and accommodation, emotional support (including encouragement and motivation) and other forms of care.

There are very few studies on the burden of EDs on caregiver within community-based samples. Rather, informal care hours are generally measured in restricted samples, such as in people currently attending a specialist treatment program or people who are admitted to hospital. The most relevant studies are summarized in Table 4.18 and in the following paragraphs.

- Rhind et al. (2016) examined caregiving for adolescent outpatients (n=144) with AN,<sup>145</sup> using a semi-structured interview process to estimate the time spent across caregiving tasks of parents (n=196) as 52.5 hours per month, or 17 hours per month when considering direct care tasks.
- Raenker et al. (2013) found the time spent caregiving by parents (n=224) and partners (n=28) for inpatients (n=178) in the United Kingdom<sup>146</sup> was 72 hours per month, or 18.3 hours per month when considering direct care tasks.
- Coomber et al. (2012) surveyed 56 carers of those with an ED through a self-reported questionnaire,<sup>147</sup> finding an average of 1 hour per week of direct treatment commitments and 78.91 hours per week of general contact. This study was excluded from the analysis as it was not clear whether general contact hours were additional to what would have been spent with the individual anyway (e.g. a parent preparing a meal for their child), while the single hour would specifically restrict the analysis to time parents use to attend medical appointments with their child.

These studies did not provide sufficient detail to estimate the incremental hours of care provided by caregivers to people with EDs. Additionally, estimating the incremental hours of care based on comparative cohorts (e.g. similar age and gender) is challenging as the literature mostly covers hours of care in people with other conditions, rather than in a group that has no other health conditions.

Consequently, the incremental hours of care were estimated based on a restricted set of activities (direct medical care, food related care, other non-food medical care or information gathering). Emotional support was excluded from the estimate as this is likely to be “care” that would be provided by the caregiver anyway. Thus, **it was assumed that the average caregiver provides an additional 4.45 hours of care per week.**

Studies in other mental health conditions have shown that caregivers may spend more time with their care receiver than the average here. For example, Hielscher et al. (2018)<sup>148</sup> found that carers

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<sup>145</sup> Rhind, C., Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K. and Lo Coco, G., (2016). The objective and subjective caregiving burden and caregiving behaviours of parents of adolescents with anorexia nervosa. *European Eating Disorders Review*, 24(4), pp.310-319.

<sup>146</sup> Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., Ayton, A., Bamford, B., Boughton, N., Connan, F., Goss, K. and Lazlo, B., (2013). Caregiving and coping in carers of people with anorexia nervosa admitted for intensive hospital care. *International Journal of Eating Disorders*, 46(4), pp.346-354.

<sup>147</sup> Coomber, K. and King, R.M., (2012). Coping strategies and social support as predictors and mediators of eating disorder carer burden and psychological distress. *Social psychiatry and psychiatric epidemiology*, 47(5), pp.789-796.

<sup>148</sup> Hielscher, E., Diminic, S., Kealton, J., Harris, M., Lee, Y.Y. and Whiteford, H., (2019). Hours of care and caring tasks performed by Australian carers of adults with mental illness: results from an online survey. *Community mental health journal*, 55(2), pp.279-295.

Hielscher et al. (2018) also included a small sample of people with BN.

are estimated to provide on average 37.2 hours of care per week to care recipients, which suggests that 4.45 hours of care per week may be conservative.

The number of people with EDs receiving informal care was based on data from CPES.<sup>149</sup> In the CPES, participants who reported eating or weight problems were also asked to identify whether they had asked a family member or friend to assist them. Approximately **23.6% indicated that they had received some form of assistance from a family member or friend**. This proportion was then multiplied by the estimated number of prevalent cases of EDs in 2018-19, indicating that **approximately 1.3 million people had received help from a caregiver for their ED in 2018-19**.

Assuming that these caregivers each provide an average of 4.45 hours of care per week, this equates to a total of 232 hours of care per caregiver per year – or 5.8 full-time working weeks per caregiver per year.<sup>150</sup> Aggregating these components, it was estimated that individuals with an ED in the United States required 5.8 million hours of care in 2018-19, which equates to 144,000 full-time working weeks.

Table 4.18: Average hours of informal care provided to people with EDs.

Source	Condition (sample size)	Hours per week
Rhind et al. (2016)	AN (n=144)	4.30
Raenker et al. (2013)	AN (n=178)	4.58
<b>Weighted average</b>		<b>4.45</b>

Source: Deloitte Access Economics analysis based on Rhind et al. (2016) and Raenker et al. (2013).

The opportunity cost of an hour of care was estimated using general population AWE and employment rates (data from the US Bureau of Labor Statistics (BLS))<sup>151</sup>. The earnings and employment rates were modelled using the best available data on the approximate age and gender of all caregivers of people aged 15 to 49 years old in the US.<sup>152</sup> Earnings were adjusted to incorporate employment benefits, using the ratio of wages and salaries to total employee compensation<sup>153</sup>. The **opportunity cost of a caregiver's time was estimated to be \$22.48 per hour**.

Thus, the total costs of **informal care for Americans with an ED was estimated to be \$6.7 billion in 2018-19**, which equates to \$1,228 per person with an ED.

#### 4.4 Efficiency losses

Taxation and transfer costs do not represent a “net cost” to society, but rather a reallocation of resources across an economy. As such, these components have not been included in the cost estimates presented in this report following the societal perspective approach proposed by Larg and Moss (2011)<sup>154</sup>. However, taxation forgone because some individuals cannot work due to an

<sup>149</sup> Alegria et al. (2016), Collaborative Psychiatric Surveys (CPES), 2001-2003. Retrieved from <<https://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/20240>>.

<sup>150</sup> Assuming a full-time working week of 40 hours per week.

<sup>151</sup> Average earnings data and employment rates were obtained for the general US population in 2020 based on publicly-available administrative data.

US Bureau of Labor Statistics (BLS). (2020). Median usual weekly earnings or full-time wage and salary workers by age, race, Hispanic or Latino ethnicity, and sex, second quarter 2019. Retrieved from <<https://www.bls.gov/charts/usual-weekly-earnings/usual-weekly-earnings-current-quarter-by-age.htm>>

US Bureau of Labor Statistics (BLS). (2020). Economic News Release: Employment Situation. Retrieved from <<https://www.bls.gov/news.release/empsit.toc.htm>>.

<sup>152</sup> National Alliance for Caregiving. (2015). Caregiving in the US 2015. NAC and the AARP Public Institute. Washington DC: Greenwald & Associates.

<sup>153</sup> US Bureau of Labor Statistics (BLS). (2019). Employer costs for employee compensation – June 2019. Retrieved from <[https://www.bls.gov/news.release/archives/ecec\\_09172019.pdf](https://www.bls.gov/news.release/archives/ecec_09172019.pdf)>.

<sup>154</sup> Larg, A., & Moss, J. R. (2011). Cost-of-illness studies. *Pharmacoeconomics*, 29(8), 653-671.

illness, like government expenditure (in transfer payments) incurred due to the illness, must be financed by levying taxation on others who can work, in order to achieve the same fiscal position as in the absence of the illness (which is the counterfactual for cost-of-illness studies)<sup>155 156</sup>.

There are a range of approaches discussed in the literature, with some scholars including efficiency losses in societal cost of illness and others arguing that these costs should be excluded. For the purposes of this report, efficiency losses (the net value of lost output) are included as costs to society resulting from increased taxation prompting individuals to switch from higher valued to lower valued economic activities<sup>157</sup>, resulting in an opportunity cost to society<sup>158</sup>.

Including efficiency losses in this report is in line with best practice recommendations made by a number of studies, including Frick et al. (2010)<sup>159</sup> who argue that it is important for efficiency losses associated with taxes and transfers be included in societal cost-of-illness studies. Further, Sindelar (1991, p.39) claims that "ignoring the [efficiency loss] underestimates the associated costs and the potential benefits of prevention and treatment" associated with illnesses. Additionally, the inclusion of efficiency losses is in line with the approach used by other published cost-of-illness studies,<sup>160</sup> although it is noted that not all cost-of-illness studies include these costs.

The following sections outline the reduced taxation revenue available to government and efficiency losses associated with taxation required to fund public healthcare and government assistance.

#### **4.4.1 Government assistance payments**

The Social Security Disability Insurance (SSDI) program is a payroll tax funded federal insurance program in the US. The government assistance payments cost associated with individuals with an ED accessing the SSDI payment was estimated.<sup>161</sup>

Based on data provided by request from the SSDI, it was found that in December 2018 the number of government assistance payment beneficiaries with a primary diagnosis of eating and tic disorders was 1,494. It was indicated that these beneficiaries may approximate those cases where an ED was the primary cause of disability. The average cost per individual receiving such payments was assumed to be equal to the average payment reported for individuals with other mental disorders (\$1,106 per month in 2018-19)<sup>162</sup>.

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<sup>155</sup> Polimeni, J. M., Vichansavakul, K., Iorgulescu, R. I., & Chandrasekara, R. (2013). Why perspective matters in health outcomes research analyses. *International Business & Economics Research Journal (IBER)*, 12(11), 1503-1512.

<sup>156</sup> Sindelar, J. L. (1991). Economic cost of illicit drug studies: Critique and research agenda. *Economic Costs, Cost-Effectiveness, Financing, and Community-Based Drug Treatment*. National Institute on Drug Abuse Research Monograph, 113, 33-45.

<sup>157</sup> Browning, E. K. (1987). On the marginal welfare cost of taxation. *The American Economic Review*, 11-23.

<sup>158</sup> Sindelar, J. L. (1991). Economic cost of illicit drug studies: Critique and research agenda. *Economic Costs, Cost-Effectiveness, Financing, and Community-Based Drug Treatment*. National Institute on Drug Abuse Research Monograph, 113, 33-45.

<sup>159</sup> Frick, K. D., Kymes, S. M., Lee, P. P., Matchar, D. B., Pezzullo, M. L., Rein, D. B., & Taylor, H. R. (2010). The cost of visual impairment: purposes, perspectives, and guidance. *Investigative ophthalmology & visual science*, 51(4), 1801-1805.

<sup>160</sup> For example, see:

- Gatt, L., Jan, S., Mondraty, N., Horsfield, S., Hart, S., Russell, J., ... & Essue, B. (2014). The household economic burden of eating disorders and adherence to treatment in Australia. *BMC psychiatry*, 14(1), 338.
- Parks, J. C., Alston, J. M., & Okrent, A. M. (2012). The Marginal External Cost of Obesity in the United States (No. 1578-2016-134032).
- Wittenborn, J. S., Zhang, X., Feagan, C. W., Crouse, W. L., Shrestha, S., Kemper, A. R., ... & Vision Cost-Effectiveness Study Group. (2013). The economic burden of vision loss and eye disorders among the United States population younger than 40 years. *Ophthalmology*, 120(9), 1728-1735.

<sup>161</sup> Given the lack of sufficient data, it was not possible to estimate the cost of alternative government assistance payments that individuals with EDs or their carers may access.

<sup>162</sup> Social Security Administration (SSA). (2019). Annual Statistical Report on Social Security Disability Insurance Program, 2018. Retrieved from

<[https://www.ssa.gov/policy/docs/statcomps/di\\_asr/2018/index.html](https://www.ssa.gov/policy/docs/statcomps/di_asr/2018/index.html)>.

Using this approach, it was calculated that there were **\$19.8 million of government assistance payments due to EDs** in the US in 2018-19.

#### **4.4.2 Lost taxation revenue**

Reduced earnings from lower employment participation and lower output result in reduced taxation revenue collected by the government. As well as forgone income taxation, there would also be a 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 multiplying an average personal income tax rate and average indirect taxation rate to lost earnings.

The average rates of taxation for personal income tax, indirect taxes and company taxes were derived based on Internal Revenue Service tax statistics data. The respective tax rates used in the calculation of efficiency losses were:

- 23.8% average personal income tax rate<sup>163</sup>, and 7.1%<sup>164</sup> average indirect tax rate; and
- 25.7%<sup>165</sup> average company tax rate.

These tax rates were then multiplied by the total productivity impacts (including informal care costs). The total lost individual income tax forgone was estimated to be \$7.1 billion (including lost caregiver taxes), while the total lost company revenue was estimated to be \$5.6 billion in 2018-19.

#### **4.4.3 Efficiency loss of taxation payments and administration**

The efficiency loss will depend on the method used to levy additional taxation revenue. To estimate the efficiency loss due to lost taxation revenue (given an assumption of no change in spending), revenue was assumed to be maintained by taxing individuals more.

Based upon an average taken across multiple academic studies conducted in the US, income tax was estimated to impose a burden of \$0.33 for every dollar of tax levied.<sup>166</sup> This approach is in line with that suggested by Sindelar (1991) who recommended taking a mid-point of available estimates, and applying the principle of conservatism in estimating efficiency losses, given the uncertainty inherent in published estimates.

The rate of efficiency loss was derived as the simple average of the following studies:

- Blomquist & Simula (2010) adjusted for the non-linearity of US tax system to calculate excess burden based on 2006 US data. They found a \$0.44 loss for every dollar of tax revenue. This included state and federal income taxes, payroll tax and sales taxes.<sup>167</sup>
- Fullerton and Ta (2017) suggested that the marginal excess burden of income tax in the US is \$0.21.<sup>168</sup>

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<sup>163</sup> Organization for Economic Cooperation and Development (OECD). (2020). *Taxing Wages 2019*. Retrieved from <<https://www.oecd.org/unitedstates/taxing-wages-united-states.pdf>>.

<sup>164</sup> Ibid.

<sup>165</sup> Pomerleau, K. (2018). The United States' Corporate Income Tax Rate is now more in line with those levied by other major nations. Retrieved from <<https://taxfoundation.org/us-corporate-income-tax-more-competitive/>>.

<sup>166</sup> Other work in the US has indicated the excess burden of levying taxation is highly variable and dependent on a range of assumptions about the structure of the tax system, and how the additional taxation is levied. For the purposes of this analysis, we have focused on more conservative estimates of the efficiency loss associated with levying additional taxation. For example, studies by Feldstein in 1999 and 2006 estimated that the efficiency loss is \$0.76 per dollar of revenue raised, or greater.

Feldstein, M. (2006). The effect of taxes on efficiency and growth (No. w12201). National Bureau of Economic Research.

<sup>167</sup> Blomquist, S., & Simula, L. (2010). Marginal deadweight loss when the income tax is nonlinear. CESifo Working Paper, No. 3053. CE 211(1), 47-60.

<sup>168</sup> Fullerton, D., & Ta, C. L. (2017). Public Finance in a Nutshell: A Cobb Douglas Teaching Tool for General Equilibrium Tax Incidence and Excess Burden (No. w23064). National Bureau of Economic Research.

- Saez et al. (2012) estimated that the marginal excess burden per dollar of federal income tax revenue levied is \$0.195 under a scenario where all income tax is proportionally increased.<sup>169</sup>
- Baicker and Skinner (2011) examined the impact of continued growth in the Medicare and Medicaid programs, finding that the cost of generating the revenue needed to finance the additional health spending is \$1.48 per dollar of revenue collected, implying the efficiency loss is \$0.48 per dollar of revenue collected.<sup>170</sup>

Table 4.19 shows the estimated reduced income and health expenditure payments and the **resulting efficiency losses, which were estimated to be \$4.8 billion in 2018-19.**

Table 4.19: Efficiency losses due to EDs in 2018-19

Cost component	Total cost (\$m)	Resulting efficiency loss (\$m)
Government assistance payments	19.8	6.5
Lost consumer taxes	5,652.9	1,865.4
Lost company taxes	5,646.9	1,863.5
Lost caregiver taxes	1,427.2	471.0
Government health expenditure	1,782.9	588.4
<b>Total</b>	<b>14,529.7</b>	<b>4,794.8</b>

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

#### 4.5 Summary of financial costs

Overall, the total cost of EDs outside the health system was estimated to be \$60.2 billion in the US in 2018-19, or \$10,977 per American with an ED. Including health system costs, **the financial costs of EDs in 2018-19 were estimated to be \$64.7 billion, or \$11,808 per person with an ED.** The largest share of these costs was accounted for by OSFED (\$22.8 billion, or 35%), followed by BED (\$19.4 billion, or 30%), BN (\$11.4 billion, or 18%) and AN (\$11.2 billion, or 17%). Other financial costs due to EDs are summarized by component and ED condition in Table 4.20 and Table 4.21.

Table 4.20: Financial costs due to EDs in 2018-19

Cost component	Total cost (\$m)	Cost per person with an ED (\$)
Health system costs	4,555.4	831
Productivity losses	48,634.3	8,874
Informal care	6,731.4	1,228
Efficiency losses	4,794.8	875
<b>Total</b>	<b>64,716.0</b>	<b>11,808</b>

Source: Deloitte Access Economics. Note: components may not sum to totals due to rounding.

<sup>169</sup> Saez, E., Slemrod, J., & Giertz, S. H. (2012). The elasticity of taxable income with respect to marginal tax rates: A critical review. *Journal of economic literature*, 50(1), 3-50.

<sup>170</sup> Baicker, K., & Skinner, J. (2011). Health care spending growth and the future of US tax rates. *Tax Policy and the Economy*, 25(1), 39-68.

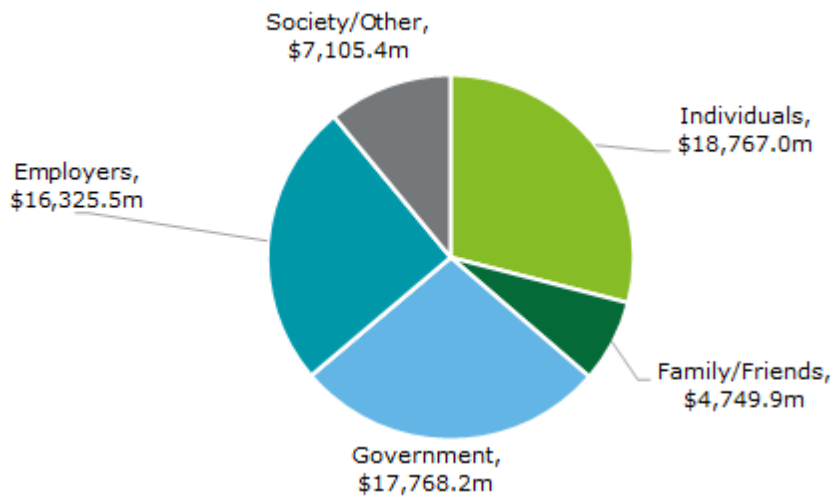
Table 4.21: Financial costs due to EDs in 2018-19

Condition	Total cost (\$m)	Cost per person with an ED (\$)
AN	11,162.6	27,359
BN	11,369.6	18,283
BED	19,384.2	9,533
OSFED	22,799.6	9,432
<b>Total</b>	<b>64,716.0</b>	<b>11,808</b>

Source: Deloitte Access Economics. Note: components may not sum to totals due to rounding.

It was estimated that individuals and their families and friends bore 36.3% of total financial costs, while government, employers and the rest of society each bore 27.5%, 25.2% and 11.0% of total financial costs respectively, as shown in Chart 4.3.

Chart 4.3: Financial costs by payer (\$ millions)



Source: Deloitte Access Economics.

# 5 Loss of wellbeing

There are substantial wellbeing losses due to EDs. This chapter adopts the burden of disease methodology to quantify the impact of EDs on wellbeing. The approach is non-financial, where the reduction in quality of life and premature mortality are measured in terms of DALYs.

## Key findings

- EDs were estimated to cost the US 1.3 million DALYs in 2018-19, which represented approximately 1.2% of the total burden of disease in the US.
- The total value of lost wellbeing was estimated to be \$326.5 billion in the US in 2018-19, by converting the DALYs to a monetized value using the VSLY. This comprised \$64.2 billion in YLLs and \$262.3 billion associated in YLDs.

### 5.1 Valuing life and death

The burden of disease methodology was developed by the World Health Organization and is a comprehensive measure of mortality and disability from conditions for populations around the world. The burden of disease methodology is a non-financial approach, where life and health can be measured in terms of DALYs. DALYs include both years of life lost due to premature death (YLLs) and years of healthy life lost due to disability (YLDs).

Disability weights are assigned to various health states, where zero represents a year of perfect health and one represents death. Other health states are given a weight between zero and one to reflect the loss of wellbeing due to a particular condition. For example, a disability weight of 0.2 is interpreted as a 20% loss in wellbeing, relative to perfect health for the duration of the condition.

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the VSL. The VSL is an estimate of the value society places on an anonymous life. The US Government collectively does not set a specified VSL dollar amount for use in policy and economic evaluations, with heterogeneity across government departments and agencies. The US Department of Transportation sets a VSL of \$10.4 million (in 2019 dollars), and advising sensitivity analysis between \$5.8 million and \$14.5 million (in 2019 dollars)<sup>171</sup>. The Environmental Protection Agency recommends a VSL of \$9.4 million (in 2019 dollars), while the Department of Health and Human Services recommended analyses be undertaken using a VSL of \$10.4 million (in 2019 dollars)<sup>172</sup>. The Office of Management and Budget suggests government organizations may set their own VSL, which should be between \$1.4 and \$13.9 million (in 2019 dollars)<sup>173</sup>. Recent data suggests a range between \$4.6 and \$15.0 million (in 2019 dollars)<sup>174</sup>. All of these estimates were adjusted from their base year to current dollars using changes in the consumer price index based on the BLS.

For this report a VSL of \$7.5 million (in 2019 dollars, inflated using changes in the consumer price index based on the BLS) was selected for estimating burden of disease costs, based on the mid-point of the Office of Management and Budget recommendation in 2003 (a VSL of \$5.5 million),

<sup>171</sup> US Department of Transportation. (2016). Guidance on the treatment of the economic value of a statistical life (VSL) in US Department of Transportation Analyses – 2016 Adjustment. Retrieved from <<https://www.transportation.gov/sites/dot.gov/files/docs/2016%20Revised%20Value%20of%20a%20Statistic%20Life%20Guidance.pdf>>.

<sup>172</sup> Office of the Assistant Secretary for Planning and Evaluation (ASPE). (2016). Guidelines for Regulatory Impact Analysis. Retrieved from <[https://aspe.hhs.gov/system/files/pdf/242926/HHS\\_RIAGuidance.pdf](https://aspe.hhs.gov/system/files/pdf/242926/HHS_RIAGuidance.pdf)>.

<sup>173</sup> Office of Management and Budget. (2017). 2017 Draft Report to Congress on the Benefits and Costs of Federal Regulations and Agency Compliance with Unfunded Mandates Reform Act. Retrieved from <[https://www.whitehouse.gov/wp-content/uploads/2017/12/draft\\_2017\\_cost\\_benefit\\_report.pdf](https://www.whitehouse.gov/wp-content/uploads/2017/12/draft_2017_cost_benefit_report.pdf)>.

<sup>174</sup> Robinson, L. A., & Hammitt, J. K. (2016). Valuing reductions in fatal illness risks: Implications of recent research. *Health Economics*, 25(8), 1039-1052.

adjusted for inflation. This value equates to a VSLY of \$294,151, which was used to convert DALYs to a monetary value.<sup>175</sup>

A discount rate of 3% was used for future burden of disease costs consistent with other costs within this report. No discounting was applied to future DALY estimates (when presented in terms of DALYs) consistent with the current GBD study methods<sup>176</sup>. Discounting of the VSLY reflects its lower future financial value due to positive time preference, risk and inflation.

## 5.2 Mortality

To estimate the value of premature mortality due to EDs, YLLs were estimated based on the age of death, the excess risk of mortality due to the condition, and the corresponding YLLs in the Standard Life Expectancy Table<sup>177</sup>.

Overall, it was estimated that there were 371,795 YLLs (with no discounting applied) associated with EDs in 2018-19. The monetary value of a YLL was discounted at a rate of 3% per annum in order to estimate the value of life years lost due to EDs in 2018-19, which was valued at \$64.2 billion.

## 5.3 Morbidity

The YLDs associated with EDs were estimated by multiplying a disability weight for each condition by the prevalence of the corresponding condition and the VSLY.

To estimate the disability weight for AN and BN, data were collected from the GBD study, and from studies on the health-related quality of life for people with EDs. The GBD provides disability weights for AN and BN, which were 0.224 and 0.223 respectively.<sup>178</sup>

As there are no representative disability weights for BED or OSFED, these were based on the difference in health utility values in people with EDs compared to the general population, following the approach taken in Haagsma et al. (2009).<sup>179</sup> The disability weights for BED and OSFED were estimated to be 0.184 and 0.115, respectively (Table 5.1). To estimate difference in utility, the following sources were used:

- Agh et al. (2016)<sup>180</sup> conducted a systematic review of the health-related quality of life in people with AN, BN and BED. The authors provided detailed SF-36 dimension scores across eight domains for each condition separately.
- An algorithm from Ara et al. (2008)<sup>181</sup> was used to convert SF-36 dimension scores to EuroQol-5D preference-based utility scores. The summarized results are provided in Table 5.1.

<sup>175</sup> The VSLY was calculated as the VSL /  $((1 - (1 + r)^{LE}) / r)$ , where  $r$  is the discount rate (3%) and LE is the average life expectancy in the US population (approximately 42 years based on period life tables).

<sup>176</sup> James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., ... & Abdollahpour, I. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1789-1858.

<sup>177</sup> Arias, E., & Xu, J. (2019). United States life tables: 2017. Retrieved from <[https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_07-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_07-508.pdf)>.

<sup>178</sup> James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., ... & Abdollahpour, I. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1789-1858.

<sup>179</sup> Haagsma, J. A., Polinder, S., Van Beeck, E. F., Mulder, S., & Bonsel, G. J. (2009). Alternative approaches to derive disability weights in injuries: do they make a difference?. *Quality of Life Research*, 18(5), 657-665.

<sup>180</sup> Agh, T., Kovács, G., Supina, D., Pawaskar, M., Herman, B. K., Vokó, Z., & Sheehan, D. V. (2016). A systematic review of the health-related quality of life and economic burdens of anorexia nervosa, bulimia nervosa, and binge-eating disorder. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, 21(3), 353-364.

<sup>181</sup> Ara, R., & Brazier, J. (2008). Deriving an algorithm to convert the eight mean SF-36 dimension scores into a mean EQ-5D preference-based score from published studies (where patient level data are not available). *Value in Health*, 11(7), 1131-1143.



- The disability weight was then based on the difference between population norm utility scores from Janssen et al. (2019)<sup>182</sup> and the resulting utility scores for each study.
- An average disability weight was derived for each type of ED, which was calculated as the simple average of the studies shown in Table 5.1, including evidence from a recent Australian study (Le et al., 2019) and study from the US (Hart et al., 2020).<sup>183, 184</sup>

Data for AN and BN are also shown to demonstrate the comparability of using this approach with the disability weights published by the GBD study. Overall, comparing the utility scores to population norms was reasonably consistent with, albeit lower than, the disability weights derived for the GBD study.<sup>185, 186</sup>

Table 5.1: Mean utility scores in populations with EDs, and implied disability weights

Condition, first author and year	Country	Mean utility in sample*	Population norm utility	Implied disability weight
<b>AN</b>				
Doll, 2005	United Kingdom	0.753	0.856	0.103
Gonzalez-Pinto, 2004	Spain	0.746	0.915	0.169
Padierna, 2000	Spain	0.706	0.915	0.209
Padierna, 2000	Spain	0.748	0.915	0.167
Rie, 2005	Netherlands	0.673	0.892	0.219
Turner, 2010	United Kingdom	0.531	0.856	0.325
<i>Average</i>				<i>0.198</i>
<b>BN</b>				
Doll, 2005	United Kingdom	0.779	0.856	0.077
Padierna, 2000	Spain	0.717	0.915	0.198
Rie, 2005	Netherlands	0.683	0.892	0.209
Turner, 2010	United Kingdom	0.643	0.856	0.213
Le, 2019	Australia	0.710	0.820	0.110
Hart, 2020	US	-	-	0.072

<sup>182</sup> Janssen, M. F., Szende, A., Cabases, J., Ramos-Goñi, J. M., Vilagut, G., & König, H. H. (2019). Population norms for the EQ-5D-3L: a cross-country analysis of population surveys for 20 countries. *The European Journal of Health Economics*, 20(2), 205-216.

<sup>183</sup> Le, L. K. D., Mihalopoulos, C., Engel, L., Touyz, S., González-Chica, D. A., Stocks, N., & Hay, P. (2019). Burden and health state utility values of eating disorders: results from a population-based survey. *Psychological medicine*, 1-8.

<sup>184</sup> Hart et al. (2020) provided utility values for health-related quality of life for a range of disordered eating behaviors including "binge-eating – at least weekly" in the past year. Of the results reported, it was assumed that this behaviour most closely resembled the diagnostic criteria for BN, BED and OSFED. The impact on utility values was moderated in the presence of BMI and gender, although the results reported in Table 5.1 were weighted by the number of participants who reported the disordered eating behaviour (110 female and 12 male). Hart, L. M., Gordon, A. R., Sarda, V., Calzo, J. P., Sonnevile, K. R., Samnaliev, M., & Austin, S. B. (2020). The association of disordered eating with health-related quality of life in US young adults and effect modification by gender. *Quality of Life Research*, 1-13.

<sup>185</sup> Estimating disability weights using preference-based utility measures can be highly dependent on the included study population. For example, the sample may have a different pattern of comorbidity compared to all people with EDs, which can impact on overall utility. As such, relying on the GBD estimates is preferred as they are based on expert opinion and extensive validation processes.

<sup>186</sup> The derived disability weights for BED and OSFED may still be quite high relative to AN and BN, although they represent the best available data in the literature. Further research should continue to focus on the impacts of BED and OSFED, and these conditions should be included in larger studies, including the Global Burden of Disease study so that the loss of wellbeing due to EDs can be monitored across countries and over time.

Condition, first author and year	Country	Mean utility in sample*	Population norm utility	Implied disability weight
<i>Average</i>				<i>0.146</i>
<b>BED</b>				
de Zwaan, 2002	US	0.528	0.825	0.297
Doll, 2005	United Kingdom	0.774	0.856	0.082
Marchesini, 2002	Italy	0.688	0.899	0.211
Padierna, 2000	Spain	0.644	0.915	0.271
Le, 2019	Australia	0.650	0.820	0.170
Hart, 2020	US	-	-	0.072
<i>Average</i>				<i>0.184</i>
<b>OSFED</b>				
Rie, 2005	Netherlands	0.69	0.892	0.205
Turner, 2010	United Kingdom	0.69	0.856	0.166
Le, 2019	Australia	0.78	0.82	0.033
Hart, 2020	US	-	-	0.072
<i>Average</i>				<i>0.119</i>

Source: Based on Agh et al. (2016), Ara et al. (2008), Janssen et al. (2019) Le et al. (2019) and Hart et al. (2020).

Note: \*Mean utility scores within each condition have been converted from SF-36 mean dimension scores using an algorithm reported by Ara et al. (2008).

Table 5.2: Final disability weights for EDs

Condition	Source	Disability weight
AN	James et al. (2018) <sup>187</sup>	0.224
BN	James et al. (2018)	0.223
BED	Derived based on Agh et al. (2016), Le et al. (2019) and Hart et al. (2020).	0.184
OSFED	Derived based on Agh et al. (2016), Le et al. (2019) and Hart et al. (2020).	0.119

Source: As noted in table.

The derived disability weights (Table 5.2) were multiplied by the prevalence of EDs in the US to estimate the YLDs associated with EDs. Overall, it was estimated that 891,874 YLDs were associated with EDs in 2018-19.

#### 5.4 Summary of loss of wellbeing

Overall, it was estimated that there were close to 1.3 million DALYs associated with EDs in 2018-19.

<sup>187</sup> James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., ... & Abdollahpour, I. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1789-1858.

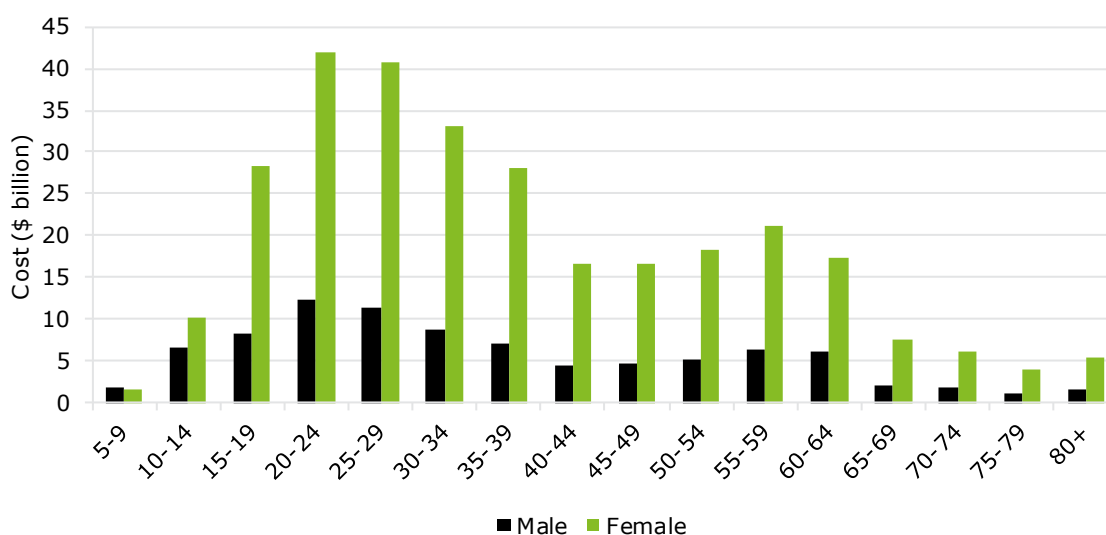
Converting the DALYs to a dollar estimate using the VSLY, the total reduction in wellbeing was valued at **\$326.5 billion in 2018-19**. DALYs were estimated to be much higher in females than in males, reflecting greater prevalence in females (Chart 5.1).

Table 5.3: Loss of wellbeing due to EDs in 2018-19

Condition	YLLs	YLDs	DALYs	DALYs (\$m)
AN	91,393	107,948	199,342	44,695
BN	138,679	36,155	174,833	47,068
BED	374,133	105,941	480,074	128,858
OSFED	287,669	121,752	409,420	105,909
<b>Total</b>	<b>891,874</b>	<b>371,795</b>	<b>1,263,669</b>	<b>326,530</b>

Source: Deloitte Access Economics. Note: components may not sum to totals due to rounding. Discounting means that YLLs will sum with YLDs to undiscounted DALYs, but in converting using the VSLY future YLLs are discounted so the result is not a simple multiplication of DALYs and the VSLY,

Chart 5.1: Loss of wellbeing due to EDs in 2018-19 (\$ billion)



Source: Deloitte Access Economics analysis.

## 6 Best practice

### Key findings

- Stepped care is an evidence-based, staged system comprising a hierarchy of interventions, from the least to the most intensive, matched to an individual's needs.
- Integrated care is characterised by the comprehensive delivery of health services, designed according to the multidimensional needs of the population and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. Stepped and integrated care are often provided in tandem.
- A paucity of evidence was found in the literature where the cost-effectiveness of stepped or integrated models of care have been evaluated. More research is needed in this area.
- For 1,000 college students, a stepped care model could yield an estimated cost savings of \$13,863.
- Stepped and integrated care models are likely to provide cost-effective treatment through better understanding of a patient's individual needs and matching care to support their symptoms.
- PHPs could be a cost-effective option, for EDs treatment, with potential savings of \$9,645 per patient, compared to inpatient care.
- Specialist outpatient care has also been shown to be dominant over inpatient treatment in terms of incremental cost-effectiveness.
- There are a broad range of treatments offered to patients with EDs that usually include a psychological or psychotherapy component.
- CBT is the most widely investigated ED treatment. Therapist-led CBT for individuals with BN has been shown to be significantly more efficacious on all three outcomes – remission, binge or purge frequencies and cognitive symptoms. While CBT appeared to demonstrate some improvements in key outcomes (BMI, ED symptoms, broader psychopathology) in AN, it was not consistently superior to other treatments.
- Approaches to prevention can be classified as universal, selected or indicated strategies.
- The cost-effectiveness of treatment interventions has been investigated; however, no overall conclusive recommendations have been drawn due to the variability in the interventions, outcome measures and findings. Studies of incremental cost effectiveness reviewed here ranged from \$19,581 per QALY to \$71,865 per DALY averted, with some studies dominant relative to selected comparators. Other outcome measures included cost per year lived without an ED (or "abstinent" case), and cost per individual with a clinically meaningful outcome.

The purpose of this chapter is to summarize the available evidence on the effectiveness and benefits of existing treatments for EDs, including stepped-based care approaches and integrated treatment compared to treatment as usual or standard care as defined in the literature (each treatment option will be described briefly). The modelling in chapter 4 identified that the average cost per person with an ED was \$8,769 in 2018-19, and the reduction in wellbeing for the average person with an ED was valued at a further \$59,579 in 2018-19 (chapter 5). Emerging literature focused on stepped and integrated care is of importance given the potential for these models to avert some of the social and economic costs of EDs in the US. Cost savings could be achieved through maximizing efficiency of treatment and effective resource usage simultaneously.

It is also important to note that a significant proportion of the current literature is focused solely on outpatient treatment delivered by itself. For example, international clinical practice guidelines recommend that overall, people with EDs should receive their treatment in an outpatient setting.

However, it is not known if outpatient care is as effective as more intensive inpatient or PHP. There is a need to undertake further trials comparing inpatient and outpatient or day care for people with EDs, when it is medically safe to consider less intensive care settings.<sup>188</sup>

Further, the design and broad implementation of efficacious ED prevention programs could also assist in reducing the significant and prolonged medical and psychosocial costs associated with EDs in the US.

This report has largely focused on quantifying the social and economic costs of tertiary prevention and interventions that support individuals already displaying characteristics of EDs. However, primary and secondary prevention are equally as important when considering ways to reduce the burden of EDs in the US. Primary prevention strategies are those that target the entire population and are not directed towards at-risk groups. Secondary prevention strategies identify and support subsets of the population who may be at higher than average risk for developing EDs. The ED field has made significant progress in translating ED risk factor research into successful primary and secondary preventive interventions.<sup>189,190,191,192,193,194</sup> While prevention is an important element in reducing the burden of EDs, evidence for primary and secondary prevention has not been summarised further in this chapter, in part because of the smaller number of studies, but also because the focus of this report was largely on tertiary prevention and intervention and the costs of EDs.

The findings of this evidence review have also identified that further research is needed to demonstrate the cost-effectiveness of stepped and integrated models of care for EDs in the US. Other individual treatment options – which are often delivered as part of more comprehensive care for EDs are discussed in section 6.3.

## 6.1 Methodology

A targeted (non-systematic) review of the scientific literature and publicly available databases was conducted to identify evidence on prevention, intervention or treatments for EDs. The review searched the PubMed and Cochrane Library databases in English to:

- Identify the population (EDs)
- Identify the intervention (prevention, intervention or treatments, stepped or integrated care)

The search was restricted to systematic literature reviews of human studies from 2010 onwards in the English language.

Additional desktop research and ad-hoc searches were performed to further investigate useful aspects of the articles analyzed. Where possible, studies conducted in the US have been included. Where this was not possible, studies from similar populations in other countries were reviewed.

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<sup>188</sup> Hay, P.J., Touyz, S., Claudino, A.M., Lujic, S., Smith, C.A. and Madden, S., (2019). Inpatient versus outpatient care, partial hospitalisation and waiting list for people with eating disorders. *Cochrane Database of Systematic Reviews*, (1).

<sup>189</sup> Dakanalis, A., Clerici, M. and Stice, E., (2019). Prevention of eating disorders: current evidence-base for dissonance-based programmes and future directions.

<sup>190</sup> Le, L.K.D., Barendregt, J.J., Hay, P. and Mihalopoulos, C., (2017). Prevention of eating disorders: a systematic review and meta-analysis. *Clinical Psychology Review*, 53, pp.46-58.

<sup>191</sup> Harrer, M., Adam, S.H., Messner, E.M., Baumeister, H., Cuijpers, P., Bruffaerts, R., Auerbach, R.P., Kessler, R.C., Jacobi, C., Taylor, C.B. and Ebert, D.D., (2019). Prevention of eating disorders at universities: A systematic review and meta-analysis. *International Journal of Eating Disorders*.

<sup>192</sup> Chua, J.Y.X., Tam, W. and Shorey, S., (2020). Research Review: Effectiveness of universal eating disorder prevention interventions in improving body image among children: a systematic review and meta-analysis. *Journal of Child Psychology and Psychiatry*, 61(5), pp.522-535.

<sup>193</sup> Linardon, J., Gleeson, J., Yap, K., Murphy, K. and Brennan, L., (2019). Meta-analysis of the effects of third-wave behavioural interventions on disordered eating and body image concerns: Implications for eating disorder prevention. *Cognitive behaviour therapy*, 48(1), pp.15-38.

<sup>194</sup> Wade, T.D. and Wilksch, S.M., (2018). Internet eating disorder prevention. *Current opinion in psychiatry*, 31(6), pp.456-461.

## 6.2 Models of care: stepped and integrated care

Stepped care is defined as an evidence based, staged system comprising a hierarchy of interventions, from the least to the most intensive, matched to the individual's needs. This model of care allows patients to "step-up" or "step-down" the intensity of their treatment, meaning that treatment is available to meet an individual's needs at the point in time that they require the treatment.

Integrated care is characterized by the comprehensive delivery of health services, designed according to the multidimensional needs of the population and delivered by a coordinated multidisciplinary team of providers working across settings.<sup>195</sup>

Often, there is little distinction between stepped and integrated care models, and these are often delivered in tandem in different care settings. However, stepped and integrated care have been separately discussed in the followings sections as they can involve different care settings – for example, stepped care for an individual may include residential care followed by an IOP program, while a program delivered solely in an outpatient setting could still be integrated care.

### 6.2.1 Stepped care

Stepped care is grounded in research evidence, clinical expertise and patient values, preferences and characteristics.<sup>196</sup> These three components of evidence-based practice are considered essential for providing optimal care in the treatment of EDs. An example of a stepped care approach for EDs is provided in Figure 6.1.

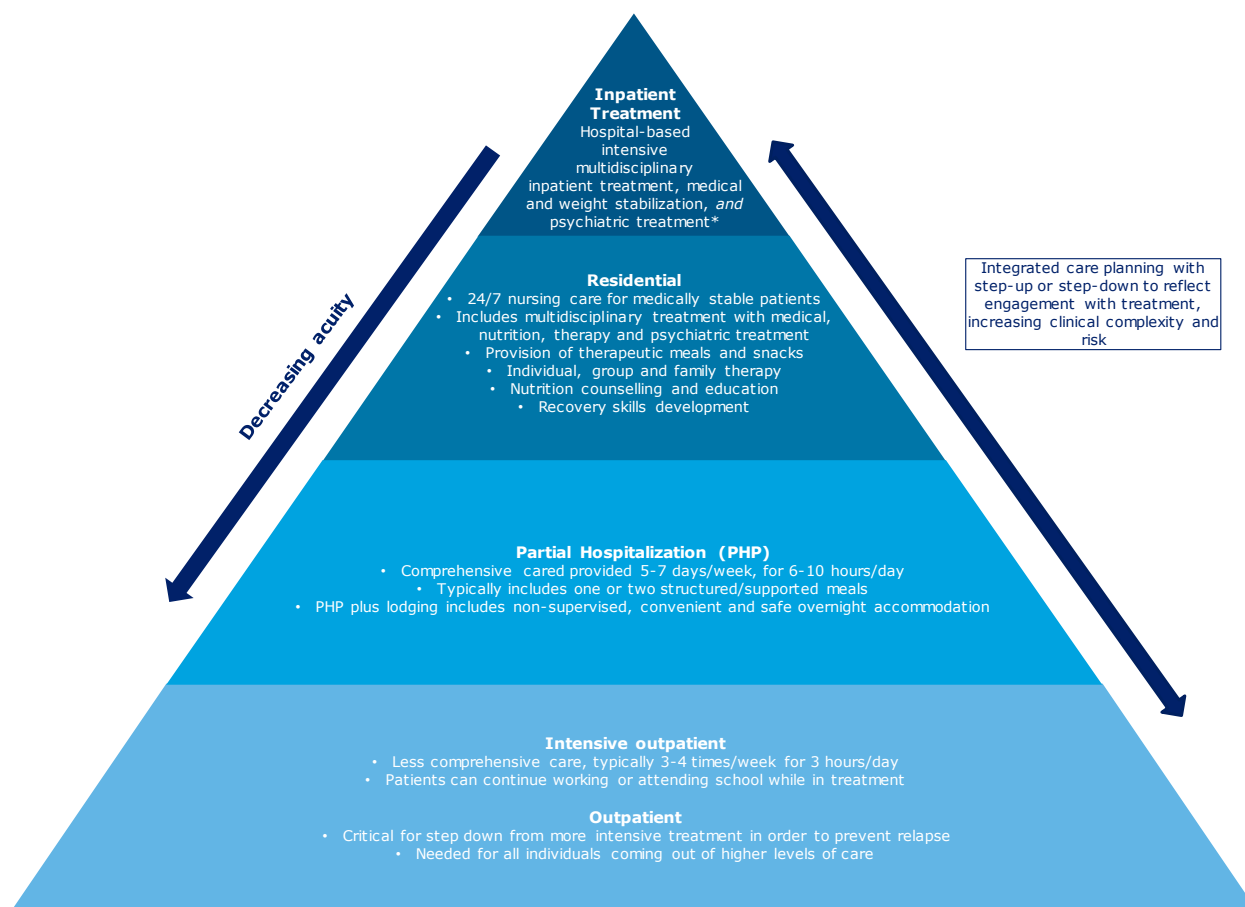
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<sup>195</sup> World Health Organization (2016) *Integrated care models: An overview*

<[http://www.euro.who.int/\\_data/assets/pdf\\_file/0005/322475/Integrated-care-models-overview.pdf](http://www.euro.who.int/_data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf)>.

<sup>196</sup> Peterson, C. B., Becker, C. B., Treasure, J., Shafran, R., & Bryant-Waugh, R. (2016). The three-legged stool of evidence-based practice in eating disorder treatment: research, clinical, and patient perspectives. *BMC medicine*, 14(1), 69.

Figure 6.1: Stepped care model for EDs



Source: Modified with permission from The Alliance for Eating Disorders Awareness (2020). Notes: \*Inpatient medical hospitalization on a medical unit specializing in EDs usually includes intensive multidisciplinary inpatient treatment, medical and weight stabilization, but doesn't always include psychiatric treatment. Inpatient psychiatric or behavioral health hospitalization specializing in ED treatment includes psychiatric treatment, plus intensive multidisciplinary treatment and medical and weight stabilization.

Several stepped care models have been reviewed in the literature. The results of these studies indicate that stepped care models may be useful in providing services to a broader range of people at risk of developing an ED, while matching the level of care to the severity of a patient's ED may make this treatment a cost-effective intervention.

There is a dearth of studies using low levels of care for AN. Stepped care involving a minimal type of intervention (e.g. self-help, or guided self-help) may be inappropriate for patients with AN due to the clinical severity of their symptoms.<sup>197</sup> However, low levels of care, such as self-help or guided self-help, have succeeded in treating a substantial subset of patients effectively.<sup>198,199,200,201</sup> While these studies have not randomized people who remain symptomatic to the next level of care

<sup>197</sup> Wilson, G.T., Vitousek, K.M. and Loeb, K.L., (2000). Stepped care treatment for eating disorders. *Journal of Consulting and Clinical Psychology*, 68(4), p.564.

<sup>198</sup> Carter, J.C., Kenny, T.E., Singleton, C., Van Wijk, M. and Heath, O., (2020). Dialectical behavior therapy self-help for binge-eating disorder: A randomized controlled study. *International Journal of Eating Disorders*, 53(3), pp.451-460.

<sup>199</sup> de Zwaan, M., Herpertz, S., Zipfel, S., Svaldi, J., Friederich, H.C., Schmidt, F., Mayr, A., Lam, T., Schade-Brittinger, C. and Hilbert, A., (2017). Effect of internet-based guided self-help vs individual face-to-face treatment on full or Subsyndromal binge eating disorder in overweight or obese patients: the INTERBED randomized clinical trial. *JAMA psychiatry*, 74(10), pp.987-995.

<sup>200</sup> König, H.H., Bleibler, F., Friederich, H.C., Herpertz, S., Lam, T., Mayr, A., Schmidt, F., Svaldi, J., Zipfel, S., Brettschneider, C. and Hilbert, A., (2018). Economic evaluation of cognitive behavioral therapy and Internet-based guided self-help for binge-eating disorder. *International Journal of Eating Disorders*, 51(2), pp.155-164.

<sup>201</sup> Striegel-Moore, R. H., DeBar, L., Wilson, G. T., Dickerson, J., Rosselli, F., Perrin, N., . . . Kraemer, H. C. (2008). Health services use in eating disorders. *Psychol Med*, 38(10), 1465-1474. doi:10.1017/s0033291707001833

(as needed for a stepped-care approach), the success of the lower level intensity treatments should be viewed as one indication that the stepped-care approach has value and should be tested more systematically.

#### Examples of stepped care programs in the US:

- Veritas Collaborative provides stepped care services across three states in the US, including North Carolina, Virginia and Georgia. The levels of care from least to most intensive are outpatient, IOP, PHP, acute residential and inpatient care.<sup>202</sup>
- The Denver Eating Recovery Center, Denver provides treatment for a multitude of EDs, including AN, ARFID, BED, BN, diabulimia, OSFED and mood and anxiety disorders.<sup>203</sup> The comprehensive ED treatment programs are housed in seven facilities in the Denver metro area. Services offered include: inpatient, residential, PHP, IOP and virtual outpatient.
- Columbia University Department of Psychiatry offers an EDs clinic and provides a comprehensive evaluation and assessment of treatment needs.<sup>204</sup> In terms of patient experience, some of the services include: outpatient treatment for adolescents, day treatment for adolescents, and inpatient treatment.
- Oliver-Pyatt Centers offer three levels of care for EDs, including a residential program, day treatment and supervised living.<sup>205</sup>
- The Emily Program treats all EDs, including AN, BN, BED, OSFED. All levels of care are offered, from 24/7 residential treatment through to outpatient services across multiple states including Minnesota, Ohio, Pennsylvania, and Washington.<sup>206</sup>
- The Center for Eating Disorders Care and Treatment provided through the University of Pittsburgh Medical Center includes an inpatient unit, and three levels of outpatient care, including: PHP, the IOP program and the outpatient clinic.<sup>207</sup>

A systematic review examined nine evidence-based clinical treatment guidelines for all specific EDs. An increased evidence-base is critical in offering clinically reliable and consistent guidance for the treatment of ED. An international comparison of these guidelines demonstrated notable commonalities and differences among the current clinical guidelines. Importantly, most of these guidelines recommended stepped care approaches to EDs. For example, first-line treatment offered in an outpatient setting, followed by day hospital treatment and more intensive treatment options thereafter. The guidelines also provided recommendations on treatment modalities, psychological interventions, medications and other treatments such as physical therapy.<sup>208</sup>

A Delphi study on stepped care for adolescents with AN involving 25 experts recommended FBT as the initial treatment for an adolescent with AN; unless the patient is medically unstable, suicidal, refusing food, or at high risk for refeeding syndrome.<sup>209</sup> Adolescents were recommended to be moved to inpatient treatment if any of these clinical features emerge during treatment in either FBT or a structured outpatient setting. Panel responses also suggested that other outpatient treatments may be added to FBT or recommended instead of FBT, if response to treatment is inadequate.<sup>210</sup> Decrease in level of care from inpatient to FBT is suggested when the indication for hospitalization has resolved, and eating has improved. Decrease from inpatient to structured

<sup>202</sup> Veritas Collaborative. (2020). *Levels of care* <<https://veritascollaborative.com/treatment-programs-and-recovery/levels-of-care/>>.

<sup>203</sup> Eating Recovery Center, Denver. (2020). *Overview* <<https://www.eatingrecoverycenter.com/recovery-centers/denver/>>.

<sup>204</sup> Columbia University Department of Psychiatry. (2020). *Eating Disorders Clinic* <<https://www.columbiapsychiatry.org/research-clinics/eating-disorders-clinic/information-patients/>>.

<sup>205</sup> Oliver-Pyatt Centers. (2020). *The OPC Program* <<https://www.oliverpyattcenters.com/why-opc/>>.

<sup>206</sup> The Emily Program. (2020). *Care we offer* <<https://emilyprogram.com/care-we-offer/>>.

<sup>207</sup> UPMC. (2020). *UPMC Center for Eating Disorders Care and Treatment* <<https://www.upmc.com/services/behavioral-health/eating-disorders/treatment/>>.

<sup>208</sup> Hilbert, A., Hoek, H.W. and Schmidt, R., (2017). Evidence-based clinical guidelines for eating disorders: international comparison. *Current opinion in psychiatry*, 30(6), p.423.

<sup>209</sup> Buchman, S., Attia, E., Dawson, L., & Steinglass, J. E. (2019). Steps of care for adolescents with anorexia nervosa—A Delphi study. *International Journal of Eating Disorders*, 52(7), 777-785.

<sup>210</sup> Ibid.



outpatient might be recommended if food intake is inadequate, or compensatory behaviors are not controlled.

A stepped care model for BED in Canada has been evaluated.<sup>211</sup> In the study, the first step of care provided to patients with BED was unguided self-help based on a cognitive-behavioral therapy (CBT) model. The second step assigned patients to 16 weeks of group psychodynamic-interpersonal psychotherapy (GPIP) or to a no-treatment control condition. The study found that the first step resulted in significant reductions in binge-eating and moderate to large reductions in EDs cognitions. In the second step, there were no significant differences in the frequency of binge-eating between the GPIP group and the control condition group. However, the GPIP group experienced a significant and large improvement in attachment avoidance and interpersonal problems, with both factors known to maintain binge-eating in the long run. A randomized trial conducted at four clinical centers in the US compared the best available treatment for BN, cognitive-behavioral therapy (CBT) augmented by fluoxetine (if indicated), and a stepped-care treatment approach.<sup>212</sup> The stepped-care approach began with therapist-assisted self-help followed by fluoxetine if the participant was predicted to be a non-responder. At the end of 18 weeks self-help treatment participants who had not achieved abstinence were offered full CBT for a further 6 months. Medication, if utilized, was continued until the 1-year follow-up assessment. At the end of 1-year follow-up the stepped care condition was significantly superior to CBT. This stepped care sequence was found to be more effective than CBT, which indicated that treatment was enhanced with a more individualized approach.

The cost of implementing a stepped care model for online prevention and treatment of EDs in US college campuses has been estimated.<sup>213</sup> The proposed models used online screening to detect individuals at risk of an ED, and offers them one of four resources:

- An online self-help universal preventive intervention (for those at low risk of ED)
- An online self-help selective prevention intervention (for those at high ED risk)
- An online guided self-help intervention (for those with a subclinical or clinical ED)
- Referral to in-person care (for those with AN or medical concerns warranting more intensive intervention).

**It was estimated that this stepped care model would yield cost savings of \$13,863 compared to standard care for 1,000 college students.**

### 6.2.2 Integrated care

Contrasted with episodic care, integrated care is designed to provide a seamless treatment experience spanning from professional care to self-care.

Figure 6.2 highlights the elements involved in integrated care models. Attributes include access to same day appointments, patient involvement and education, a multidisciplinary team consisting of a range of specialists, effective communication, family involvement, risk management and quality cost-benefit decision making.<sup>214</sup>

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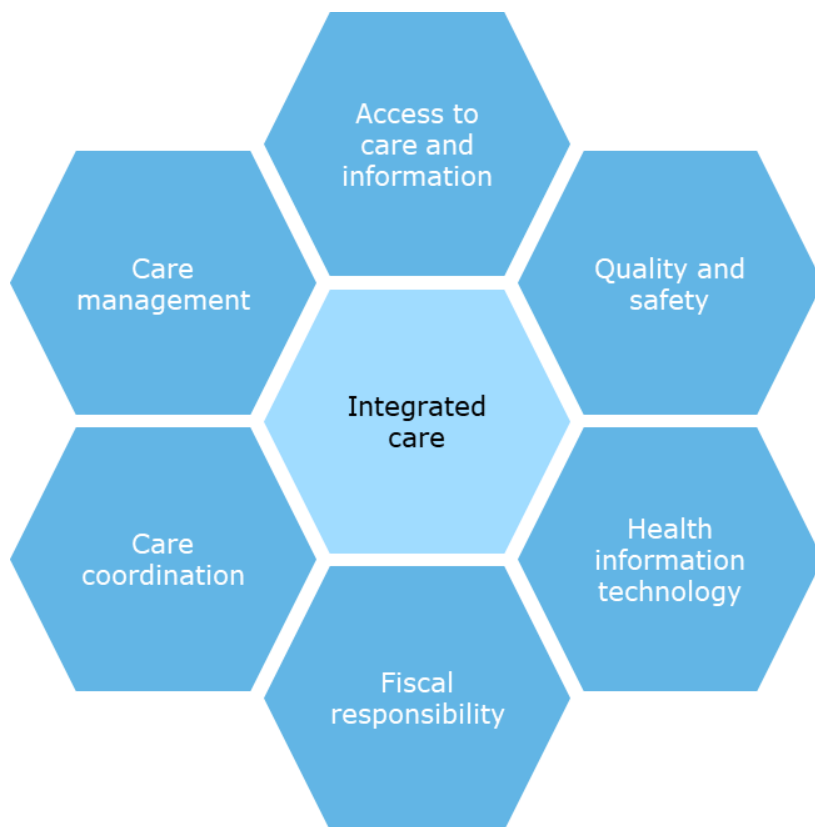
<sup>211</sup> Tasca, G. A., Koszycki, D., Brugnera, A., Chyurlia, L., Hammond, N., Francis, K., ... & Beaulac, J. (2019). Testing a stepped care model for binge-eating disorder: a two-step randomized controlled trial. *Psychological medicine*, 49(4), 598-606.

<sup>212</sup> Mitchell, J. E., Agras, S., Crow, S., Halmi, K., Fairburn, C. G., Bryson, S., & Kraemer, H. (2011). Stepped care and cognitive-behavioural therapy for bulimia nervosa: randomised trial. *The British Journal of Psychiatry*, 198(5), 391-397.

<sup>213</sup> Kass, A. E., Balantekin, K. N., Fitzsimmons-Craft, E. E., Jacobi, C., Wilfley, D. E., & Taylor, C. B. (2017). The economic case for digital interventions for eating disorders among United States college students. *International Journal of Eating Disorders*, 50(3), pp.250-258.

<sup>214</sup> World Health Organization. (2016). *Integrated care models: An overview* <[http://www.euro.who.int/data/assets/pdf\\_file/0005/322475/Integrated-care-models-overview.pdf](http://www.euro.who.int/data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf)>.

Figure 6.2: Elements of the integrated care model



Source: Adapted from Bend Memorial Clinic (2020).

Integrated care typically starts with a primary care provider making an initial determination of a patient’s problem, and are usually the first health professional to encounter an individual with an ED.<sup>215</sup> Yet, most ED cases typically go undetected in these primary care settings. This means that without detection appropriate care cannot be provided to a person with an ED.<sup>216</sup>

**Example of integrated care in the US:**

The Residential Eating Disorders Consortium is a professional association, formed in 2011 for ED treatment providers. The association is focused on standards, policy, research, and best practices for EDs. Residential Eating Disorders Consortium member programs are required to provide 24-hour care that meets the Residential Eating Disorders Consortium established standards, as well as offering day treatments for patients. Many programs also offer day treatment, IOP and outpatient treatment. Member programs represent the entire spectrum of ED care.<sup>217</sup> Incorporating the elements of the integrated care model, member programs of the REDC offer care management, care coordination and access to care and information through psychotherapeutic, nutritional, medical, and psychiatric interventions and education in relapse prevention techniques.

A review of the relevant literature identified several types of treatment that can be used in an

<sup>215</sup> Striegel-Moore, R.H., DeBar, L., Wilson, G.T., Dickerson, J., Rosselli, F., Perrin, N., Lynch, F. and Kraemer, H.C., (2008). Health services use in eating disorders. *Psychological medicine*, 38(10), pp.1465-1474.

<sup>216</sup> Buchholz, L.J., King, P.R. and Wray, L.O., (2017). Identification and management of eating disorders in integrated primary care: recommendations for psychologists in integrated care settings. *Journal of clinical psychology in medical settings*, 24(2), pp.163-177.

<sup>217</sup> Residential Eating Disorders Consortium. (2020). *What is REDC* <<http://www.residentialeatingdisorders.org/what-is-residential-eating-disorders-treatment/>>.

integrated care setting. These included FBT, CBT, nutritional management, interpersonal psychotherapy and specialist supported clinical management (pharmacotherapy).

The effectiveness of individualized, integrative outpatient treatment for females with AN and BN who received outpatient EDs treatment in the PHP, the IOP program, or a combination of the two programs has been evaluated.<sup>218</sup> After 13 weeks of treatment, patients with AN and BN experienced significant reductions in ED symptoms and attitudes. BN patients experienced a significant reduction in binge-eating, and on average, AN patients experienced a statistically significant increase in weight.

PHP could provide an alternative to costly inpatient and residential treatment. PHPs offer intermediate levels of care necessary for patients who require monitoring and treatment daily, but do not require 24-hour care.

Research undertaken by Hayes et al. (2019) indicated that PHP programs are a critical part of the treatment continuum for people with EDs, as they provide an alternative to costly and restrictive inpatient and residential programs.<sup>219</sup> The researchers collected data from a service specializing in the acute treatment of EDs, which included both PHP and IOP programs. In a large sample of patients, 89.6% of patients entered the program through PHP and 36.3% of those patients transitioned to IOP. 56.3% of patients had OSFED, 19.3% AN, 12.3% BN and 12.0% BED. The program provided group treatment for three (IOP) to six (PHP) hours per day, three to five days a week. Treatment included participation in therapeutic process and skills groups, expressive therapy and spirituality group, medication management with psychiatrists, weekly individual case management sessions, and family sessions. Over the course of the treatment, patients experienced improvements in ED symptomatology, functional impairment, quality of life, and depression. This study contributes to the small but growing literature on the economic and clinical benefits that can be obtained through PHPs. PHP can be considered a viable and effective option for patients requiring more intensive treatment.

Integrated FBT and dialectical behavior therapy, which included an amalgamation of individual, family, multi-family and parent-only components delivered 6 days per week for 3-10 hours per day for adolescent patients with BN has demonstrated promising efficacy in reducing core BN symptomatology, including a significant reduction of bingeing and purging episodes.<sup>220</sup>

Other partial integrated care approaches investigated in the literature are summarized in Table 6.1.

Table 6.1: Partial integrated care approaches

Reference	Population	Intervention	Comparator	Outcomes
Wierenga, 2017 <sup>221</sup>	AN (adults)	Neurobiologically-informed 5-day multifamily treatment. The	-	Low attrition and high acceptability. 62% of patients who completed follow up

<sup>218</sup> Freudenberg, C., Jones, R. A., Livingston, G., Goetsch, V., Schaffner, A., & Buchanan, L. (2016). Effectiveness of individualized, integrative outpatient treatment for females with anorexia nervosa and bulimia nervosa. *Eating disorders*, 24(3), 240-254.

<sup>219</sup> Hayes, N. A., Welty, L. J., Slesinger, N., & Washburn, J. J. (2019). Moderators of treatment outcomes in a partial hospitalization and intensive outpatient program for eating disorders. *Eating disorders*, 27(3), 305-320.

<sup>220</sup> Murray, S. B., Anderson, L. K., Cusack, A., Nakamura, T., Rockwell, R., Griffiths, S., & Kaye, W. H. (2015). Integrating family-based treatment and dialectical behavior therapy for adolescent bulimia nervosa: preliminary outcomes of an open pilot trial. *Eating Disorders*, 23(4), 336-344.

<sup>221</sup> Wierenga, C. E., Hill, L., Knatz Peck, S., McCray, J., Greathouse, L., Peterson, D., ... & Kaye, W. H. (2018). The acceptability, feasibility, and possible benefits of a neurobiologically-informed 5-day multifamily treatment for adults with anorexia nervosa. *International Journal of Eating Disorders*, 51(8), 863-869.

Reference	Population	Intervention	Comparator	Outcomes
		treatment involved an intake coordinator, three clinicians, a dietitian, a physician and a clinical administrative assistant		assessments achieved full or partial remission at follow up.
Williams, 2010 <sup>222</sup>	EDs	Community Outreach Partnership Program. The program combines a team approach, whereby both community and hospital services assist clients	-	Significant improvements in global distress scores, hopelessness, BMI and EDs symptoms
Gowers, 2010 <sup>223</sup>	AN (adolescents)	Inpatient compared with outpatient treatment, and routine treatment in Child and Adolescent Mental Health Services	Specialized treatment	There was significant improvement in all groups at each time point (1-, 2- and 5-year follow-ups). The specialist outpatient program was the dominant treatment
Hughes, 2014 <sup>224</sup>	AN (adolescents)	FBT	Hospital inpatient admissions, readmissions and length of stay for EDs management	Between 2006-2010 the total number of admissions declined by 56%, and the total number of persons admitted declined by 33%.
Watson, 2013 <sup>225</sup>	AN	Evidence-based practice for the treatment of AN	-	The strongest evidence points to the use of FBT for the treatment of AN in adolescents. No specific approach

<sup>222</sup> Williams, K. D., Dobney, T., & Geller, J. (2010). Setting the eating disorder aside: An alternative model of care. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, 18(2), 90-96.

<sup>223</sup> Gowers, S. G., Clark, A. F., Roberts, C., Byford, S., Barrett, B., Griffiths, A., ... & Roots, P. (2010). A randomised controlled multicentre trial of treatments for adolescent anorexia nervosa including assessment of cost-effectiveness and patient acceptability—the TOuCAN trial. *Health Technol Assess*, 14(15), 1-98.

<sup>224</sup> Hughes, E. K., Le Grange, D., Court, A., Yeo, M., Campbell, S., Whitelaw, M., ... & Sawyer, S. M. (2014). Implementation of family-based treatment for adolescents with anorexia nervosa. *Journal of Pediatric Health Care*, 28(4), 322-330.

<sup>225</sup> Watson, H. J., & Bulik, C. M. (2013). Update on the treatment of anorexia nervosa: review of clinical trials, practice guidelines and emerging interventions. *Psychological medicine*, 43(12), 2477-2500.

Reference	Population	Intervention	Comparator	Outcomes
				has shown to be superior for adults.

Source: As noted in table.

### 6.2.3 Cost-effectiveness of stepped and integrated models of care

There is a limited amount of literature where the cost-effectiveness of stepped and integrated models of care have been evaluated. Based on the available literature, it is likely that there are significant savings associated with accurately matching the care that a patient receives with the severity of their condition. Savings are also likely to be achieved from intervening at an earlier stage, such as the internet-based self-help treatments proposed by Machado et al. (2019).<sup>226</sup> This was reflected in the findings from Kass et al. (2017) where the implementation of an online self-help tools was estimated to save \$13,863 per 1,000 college students compared to usual care.<sup>100</sup>

Crow et al. (2013) reviewed the cost-effectiveness of stepped care treatment for patients with BN. The study followed 293 women who met the DSM-IV criteria for BN. The patients received stepped care treatment or CBT. During the study, quality of life ratings improved significantly with treatment, and the time burden upon family/significant others diminished substantially. The ICER was \$12,146 per person who abstained from BN behaviors for stepped care and \$20,317 for CBT. The authors demonstrated that stepped care was more effective and less expensive, indicating that stepped care was the superior treatment compared to CBT. Quality of life was also shown to improve with treatment, with more successful treatment associated with a greater improvement in quality of life. The study highlighted statistical significance for a time-by-treatment-response interaction, with individuals achieving abstinence reporting greater improvement in quality of life, compared to those who did not achieve abstinence.

The integrated care model is also likely to provide cost-effective treatment through better understanding of a patient’s individual needs and matching care to support their symptoms. Hay et al. (2019) suggested that PHPs can save \$9,645 per patient over inpatient care.<sup>106</sup> Another study, Gowers et al. (2010) found specialist outpatient care to be dominant over inpatient treatment in terms of incremental cost-effectiveness, although it is noted that this study was conducted in the United Kingdom where care models can be substantially different.<sup>227</sup> An intervention that is economically dominant is one that is both clinically superior and cost saving compared to another intervention.<sup>228</sup>

### 6.3 Other treatments for EDs

There are a broad range of specific treatments that can be offered to patients with EDs, either as part of stepped and integrated care, or in isolation as a single treatment. These treatments can include: (1) individual therapy; (2) CBT; (3) FBT; (4) hospitalization; (5) internet-based treatment; (6) physical therapy; (7) pharmaceuticals; and (8) other complementary therapies. An overview of the effectiveness of these treatments is provided in section 6.3.1 and section 6.3.2. Several economic evaluations that describe the impact of these treatments on the social and economic costs of EDs have been summarized in section 6.3.3, although it is noted that there is comparatively limited evidence on the economic benefits (as opposed to the clinical benefits) of these treatments in the US.

<sup>226</sup> Machado, P. P., & Rodrigues, T. F. (2019). Treatment delivery strategies for eating disorders. *Current opinion in psychiatry*, 32(6), 498-503.

<sup>227</sup> Gowers, S.G., Clark, A.F., Roberts, C., Byford, S., Barrett, B., Griffiths, A., Edwards, V., Bryan, C., Smethurst, N., Rowlands, L. and Roots, P., (2010). A randomised controlled multicentre trial of treatments for adolescent anorexia nervosa including assessment of cost-effectiveness and patient acceptability—the TOUCAN trial. *Health Technol Assess*, 14(15), pp.1-98.

<sup>228</sup> Cohen, D.J. and Reynolds, M.R., (2008). Interpreting the results of cost-effectiveness studies. *Journal of the American College of Cardiology*, 52(25), pp.2119-2126.

### 6.3.1 Psychological-based treatments

There are a broad range of psychological-based treatments that can be offered to patients with EDs, which can be delivered on an individual basis, as part of a group or with their families.

Individualized regular (weekly or more frequent) outpatient therapy for EDs is regarded as an appropriate approach where the person is medically stable and can attend regularly.<sup>229</sup> Several psychological therapies may be used in the outpatient care of older adolescents and adults. These include psychodynamic, cognitive behavioral or interpersonal therapy, or combinations and variants of these, with care offered in individual sessions. Limited conclusions have been drawn about the effects of specific individual psychological therapies for AN in adults or older adolescents.<sup>230</sup> Guided self-help, including a CBT element along with a self-help book may be a beneficial, first-line treatment for reducing bingeing and purging symptoms.<sup>231, 232</sup>

CBT is the most widely investigated ED treatment.<sup>233</sup> CBT seeks to help patients overcome difficulties by identifying and altering dysfunctional thinking, behavior, and emotional responses/ behaviors.<sup>234</sup> Cognitive and attentional biases towards food/ eating/ shape-related stimuli are a significant feature in ED presentations. CBT uses structured, time-limited, directive, focused on the present behavioral therapy to address many of the problems that are often a feature of EDs (including depression, anxiety, low self-esteem, obsessions/compulsions).

In AN, CBT has demonstrated effectiveness as a means of improving treatment adherence and minimizing dropout among patients.<sup>235</sup> While CBT appeared to demonstrate some improvements in key outcomes (BMI, ED symptoms, broader psychopathology), it was not consistently superior to other treatments (including dietary counseling, non-specific supportive management, interpersonal therapy, behavioral family therapy).<sup>236</sup>

Therapist-led CBT for individuals with BN has been shown to be significantly more efficacious than comparators at post-treatment on all three outcomes – remission, binge or purge frequencies or cognitive symptoms.<sup>237, 238</sup> Therapist-led CBT has also been seen to lead to higher rates of abstinence from binge-eating and improved eating related psychopathology and a decrease in Eating Disorder Examination (EDE)-Q scores.<sup>239, 240</sup>

Family therapy approaches relate to a range of approaches, derived from different theories, that involve the family in treatment. This includes therapies developed on the basis of dominant family systems theories, approaches that are based on or broadly similar to the FBT derived from the Maudsley model, approaches that incorporate a focus on cognitive restructuring, as well as

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<sup>229</sup> Hay, P. J., Claudino, A. M., Touyz, S., & Elbaky, G. A. (2015). Individual psychological therapy in the outpatient treatment of adults with anorexia nervosa. *Cochrane Database of Systematic Reviews*, (7).

<sup>230</sup> Ibid.

<sup>231</sup> Traviss-Turner, G. D., West, R. M., & Hill, A. J. (2017). Guided self-help for eating disorders: A systematic review and metaregression. *European Eating Disorders Review*, 25(3), 148-164.

<sup>232</sup> Allen, S., & Dalton, W. T. (2011). Treatment of eating disorders in primary care: a systematic review. *Journal of health psychology*, 16(8), 1165-1176.

<sup>233</sup> Linardon, J., Wade, T. D., de la Piedad Garcia, X., & Brennan, L. (2017). The efficacy of cognitive-behavioral therapy for eating disorders: A systematic review and meta-analysis. *Journal of consulting and clinical psychology*, 85(11), 1080-1094.

<sup>234</sup> Galsworthy-Francis, L., & Allan, S. (2014). Cognitive behavioral therapy for anorexia nervosa: A systematic review. *Clinical psychology review*, 34(1), 54-72.

<sup>235</sup> Ibid.

<sup>236</sup> Ibid.

<sup>237</sup> Linardon, J., Wade, T. D., de la Piedad Garcia, X., & Brennan, L. (2017). The efficacy of cognitive-behavioral therapy for eating disorders: A systematic review and meta-analysis. *Journal of consulting and clinical psychology*, 85(11), 1080-1094.

<sup>238</sup> Peat, C. M., Berkman, N. D., Lohr, K. N., Brownley, K. A., Bann, C. M., Cullen, K., ... & Bulik, C. M. (2017). Comparative effectiveness of treatments for binge-eating disorder: Systematic review and network meta-analysis. *European Eating Disorders Review*, 25(5), 317-328.

<sup>239</sup> Brownley, K. A., Berkman, N. D., Peat, C. M., Lohr, K. N., Cullen, K. E., Bann, C. M., & Bulik, C. M. (2016). Binge-eating disorder in adults: a systematic review and meta-analysis. *Annals of Internal Medicine*, 165(6), 409-420.

<sup>240</sup> de Jong, M., Schoorl, M., & Hoek, H. W. (2018). Enhanced cognitive behavioural therapy for patients with eating disorders: A systematic review. *Current opinion in psychiatry*, 31(6), 436-444.

approaches that involve the family without articulation of a theoretical approach.<sup>241</sup> FBT has a behavioral and educative focus.

Family therapy approaches may be effective compared to treatment as usual - standard treatment delivered by a multidisciplinary team and including medical and psychological care and education services - in the short term.<sup>242</sup> There was insufficient evidence to determine whether one type of family therapy approach is more effective than another. Although there does not appear to be a significant difference between FBT and individual therapy when measured at the end of treatment, when measured at 6–12-month follow-up, FBT is superior.<sup>243</sup> Family therapy focusing on symptom interruption of eating disordered behaviors should be recommended as the first line of treatment for adolescents with EDs.<sup>244</sup>

Clinical recommendations to further assist psychologists to undertake their role in this setting have been developed.<sup>245</sup> Buchholz et al. (2017) provided recommendations on the use of validated screening and assessment tools that psychologists can use, and if required, can refer patients on a case-by-case basis to a specialized clinic. The screening assessment tools could include: Questionnaire on Eating and Weight Patterns-5 (QEWP-5); Eating Disorders Examination Questionnaire (EDE-Q), Eating Disorder Diagnostic Scale (EDDS), and the SCOFF questionnaire. The authors suggested that preliminary management should be actioned next. This includes the management of acute safety concerns; use of a stepped-care approach; discussing relevant treatment options with patients; and engaging in routine outcome monitoring to track changes in ED symptoms. Additional treatment considerations include provision of patient-centered care; viewing ED management through an interdisciplinary lens; and engaging in ongoing education for EDs. Primary care psychologists can play a critical role in improving the early detection of EDs, by capitalizing on their mental health expertise, undergoing assessment training, and maintaining knowledge of the prevalence, symptomatology, comorbidities and treatment options for EDs. Primary care psychologists can also work collaboratively with multidisciplinary clinicians to improve treatment and referral outcomes for patients.

### 6.3.2 Other treatments for EDs

A range of other treatments for EDs have been investigated. These include CBT-type treatments delivered through the internet-based treatments, physical therapy, antipsychotics, and complementary medicine approaches. A summary of the evidence base for other treatments is provided in Table 6.2.

Table 6.2: Summary of evidence for other treatments for EDs

Reference	Population	Intervention(s)	Comparator(s)	Outcomes
Aardoom et al. (2013) <sup>246</sup>	EDs	Review of internet-delivered treatment interventions	Waiting list control	Significant improvements in symptomatology for individuals with less

<sup>241</sup> Fisher, C. A., Skocic, S., Rutherford, K. A., & Hetrick, S. E. (2019). Family therapy approaches for anorexia nervosa. *Cochrane Database of Systematic Reviews*, (5).

<sup>242</sup> Ibid.

<sup>243</sup> Couturier, J., Kimber, M., & Szatmari, P. (2013). Efficacy of family-based treatment for adolescents with eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders*, 46(1), 3-11.

<sup>244</sup> Ibid.

<sup>245</sup> Buchholz, L.J., King, P.R. and Wray, L.O., (2017). Identification and management of eating disorders in integrated primary care: recommendations for psychologists in integrated care settings. *Journal of clinical psychology in medical settings*, 24(2), pp.163-177.

<sup>246</sup> Aardoom, J. J., Dingemans, A. E., Spinhoven, P., & Van Furth, E. F. (2013). Treating eating disorders over the internet: a systematic review and future research directions. *International Journal of Eating Disorders*, 46(6), 539-552.

Reference	Population	Intervention(s)	Comparator(s)	Outcomes
				comorbid psychopathology
Barakat et al. (2019) <sup>247</sup>	EDs	Review of digital intervention CBT eTherapy	Wait list control/no control group	Reduced ED symptoms, comorbid depression and anxiety
Loucas et al. (2014) <sup>248</sup>	EDs	Review of CBT-based eTherapy	Wait list control	Small reductions in vomiting, binge-eating and laxative misuse
Schlegl et al. (2015) <sup>249</sup>	AN and BN	Review of computer and internet-based interventions (CBIs)	Wait list control	Guided CBIs led to reductions in bingeing and purging and global ED pathology in BN
Vancampfort et al. (2013) <sup>250</sup>	BED	Review of physical therapy interventions	Various, including placebo, control intervention or standard care	Aerobic activities reduced the number of binges
Blanchet et al. (2018) <sup>251</sup>	BED	Review of physical activity interventions	No physical activity, or other methods of treatment	Reduction of binge-eating episodes and abstinence from binge eating
Vancampfort et al. (2014) <sup>252</sup>	AN and BN	Review of physical therapy interventions	Usual care or wait list control	Lowered scores of eating pathology and depressive symptoms in both AN and BN patients

<sup>247</sup> Barakat, S., Maguire, S., Smith, K. E., Mason, T. B., Crosby, R. D., & Touyz, S. (2019). Evaluating the role of digital intervention design in treatment outcomes and adherence to eTherapy programs for eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders*, 52(10), 1077-1094.

<sup>248</sup> Loucas, C. E., Fairburn, C. G., Whittington, C., Pennant, M. E., Stockton, S., & Kendall, T. (2014). E-therapy in the treatment and prevention of eating disorders: A systematic review and meta-analysis. *Behavior research and therapy*, 63, 122-131.

<sup>249</sup> Schlegl, S., Bürger, C., Schmidt, L., Herbst, N., & Voderholzer, U. (2015). The potential of technology-based psychological interventions for anorexia and bulimia nervosa: a systematic review and recommendations for future research. *Journal of medical Internet research*, 17(3), e85.

<sup>250</sup> Vancampfort, D., Vanderlinden, J., De Hert, M., Adamkova, M., Skjaerven, L. H., Catalan-Matamoros, D., ... & Probst, M. (2013). A systematic review on physical therapy interventions for patients with binge-eating disorder. *Disability and rehabilitation*, 35(26), 2191-2196.

<sup>251</sup> Blanchet, C., Mathieu, M. È., St-Laurent, A., Fecteau, S., St-Amour, N., & Drapeau, V. (2018). A systematic review of physical activity interventions in individuals with binge-eating disorders. *Current obesity reports*, 7(1), 76-88.

<sup>252</sup> Vancampfort, D., Vanderlinden, J., De Hert, M., Soundy, A., Adamkova, M., Skjaerven, L.H., Catalan-Matamoros, D., Lundvik Gyllensten, A., Gomez-Conesa, A. and Probst, M., (2014). A systematic review of physical therapy interventions for patients with anorexia and bulimia nervosa. *Disability and rehabilitation*, 36(8), pp.628-634.



Reference	Population	Intervention(s)	Comparator(s)	Outcomes
Lebow et al. (2013) <sup>253</sup>	AN	Antipsychotics	Placebo	Atypical antipsychotics had no significant effect on eating disorder cognitions
Beauchamp et al. (2016) <sup>254</sup>	AN; BN	Bright light therapy	Dim red-light placebo or treatment as usual	Significant reductions in depressive symptoms in AN and BN; significant decreases in binge-eating episodes and purge frequency in BN
Fogarty et al. (2016) <sup>255</sup>	BN	Complementary and alternative medicine	Wait lists, placebo, pharmacotherapy, treatment as usual	No benefits to the ED
Linardon et al. (2017b) <sup>256</sup>	EDs	Third-wave therapies: dialectical behavioral therapy, schema therapy, compassion focused therapy, mindfulness-based interventions or acceptance and commitment therapy	Active comparators, or CBT	Symptom improvements; non-superior to comparators
Godfrey et al. (2015) <sup>257</sup>	BED	Mindfulness-based interventions	Waiting list, treatment as usual	Moderate reductions to binge-eating

Source: As noted in table

### 6.3.3 Economic and clinical evaluations of treatment interventions for EDs

The existing literature as to the economic and clinical evaluations of treatment interventions for EDs is summarized in Table 6.3. It is noted that no conclusive recommendations as to the most

<sup>253</sup> Lebow, J., Sim, L. A., Erwin, P. J., & Murad, M. H. (2013). The effect of atypical antipsychotic medications in individuals with anorexia nervosa: A systematic review and meta-analysis. *International Journal of Eating Disorders*, 46(4), 332-339.

<sup>254</sup> Beauchamp, M. T., & Lundgren, J. D. (2016). A Systematic Review of Bright Light Therapy for Eating Disorders. *The primary care companion for CNS disorders*, 18(5).

<sup>255</sup> Fogarty, S., Smith, C. A., & Hay, P. (2016). The role of complementary and alternative medicine in the treatment of eating disorders: A systematic review. *Eating behaviors*, 21, 179-188.

<sup>256</sup> Linardon, J., Fairburn, C. G., Fitzsimmons-Craft, E. E., Wilfley, D. E., & Brennan, L. (2017). The empirical status of the third-wave behavior therapies for the treatment of eating disorders: A systematic review. *Clinical psychology review*, 58, 125-140.

<sup>257</sup> Godfrey, K. M., Gallo, L. C., & Afari, N. (2015). Mindfulness-based interventions for binge-eating: a systematic review and meta-analysis. *Journal of behavioral medicine*, 38(2), 348-362.

cost-effective interventions can be drawn due to the variability in the measured interventions and methodological differences, which limit the comparability across studies.<sup>258</sup>

Table 6.3: Economic and clinical evaluations of treatment interventions for EDs

Reference	Population	Country year of pricing	Intervention	Comparator	Outcomes
Aardoom et al. (2016) <sup>259</sup>	Females older than 16 with self-reported ED symptoms	Netherlands (Euro), 2015	<i>Internet-based intervention</i> (with and without therapist support)	Waitlist	The intervention without therapist support were dominant to waitlist control
Crow and Nyman (2004) <sup>260</sup>	AN patients	US, 2002	"Adequate care"*	"Usual care"*	ICER of \$30,180 per year of life saved
Byford et al. (2007) <sup>261</sup>	Adolescents aged 12-18 with AN	United Kingdom, 2003	Specialized outpatient treatment	Psychiatric inpatient treatment, usual care	Specialized outpatient treatment was dominant compared to comparators
Egger et al. (2016) <sup>262</sup>	Females older than 16 with AN and sub-AN	Germany (Euro), 2008	Focal psychodynamic therapy (FPT), CBT	Usual care	FPT and CBT were dominant compared to usual care, FPT was dominant compared to CBT

<sup>258</sup> Le, L. K. D., Hay, P., & Mihalopoulos, C. (2018). A systematic review of cost-effectiveness studies of prevention and treatment for eating disorders. *Australian & New Zealand Journal of Psychiatry*, 52(4), 328-338.

<sup>259</sup> Aardoom, J. J., Dingemans, A. E., van Ginkel, J. R., Spinhoven, P., Van Furth, E. F., & Van den Akker-van Marle, M. E. (2016). Cost-utility of an internet-based intervention with or without therapist support in comparison with a waiting list for individuals with eating disorder symptoms: a randomized controlled trial. *International journal of eating disorders*, 49(12), 1068-1076.

<sup>260</sup> Crow, S. J., & Nyman, J. A. (2004). The cost-effectiveness of anorexia nervosa treatment. *International Journal of Eating Disorders*, 35(2), 155-160.

<sup>261</sup> Byford, S., Barrett, B., Roberts, C., Clark, A., Edwards, V., Smethurst, N., & Gowers, S. G. (2007). Economic evaluation of a randomised controlled trial for anorexia nervosa in adolescents. *The British Journal of Psychiatry*, 191(5), 436-440.

<sup>262</sup> Egger, N., Wild, B., Zipfel, S., Junne, F., Konnopka, A., Schmidt, U., ... & von Wietersheim, J. (2016). Cost-effectiveness of focal psychodynamic therapy and enhanced cognitive-behavioural therapy in out-patients with anorexia nervosa. *Psychological Medicine*, 46(16), 3291-3301.

Reference	Population	Country year of pricing	Intervention	Comparator	Outcomes
Koran et al. (1995) <sup>263</sup>	Female adults with BN	US, 1993	CBT, desipramine (16 or 24 - weeks), CBT+ desipramine (16 or 24 weeks)		Desipramine 16 weeks appeared to be the most cost-effective
Crow et al. (2009) <sup>264</sup>	Female adults with BN	US, 2005	Face to face CBT, Telemedicine CBT	-	ICER of \$83,845 per abstinent case
Crow et al. (2013) <sup>265</sup>	Adults 18 years and older with BN	US, 2005	Stepped care, CBT+fluoxetine	-	Stepped care was dominant compared to CBT
Agh et al. (2016) <sup>266</sup>	Adults with BED	US, 2013	Lisdexamfetamine	Placebo	ICER of \$27,618 per QALY gained
Lynch et al. (2010) <sup>267</sup>	Adults with BED	US, 2006	CBT-guided self help	Usual care	CBT-guided self help dominant to usual care

Source: Adapted from Le et al. (2018). ICER = incremental cost-effectiveness ratio. QALY = quality adjusted life year. Notes: \*From Crow and Nyman (2004), the "adequate care" approach to treatment represents a more traditional treatment approach involving inpatient weight restoration to close to 100% of ideal body weight followed by more extensive and aggressive follow-up care. The "usual care" model represents an approach to treatment commonly supported by third-party payers in the United States.

<sup>263</sup> Koran, L. M., Agras, W. S., Rossiter, E. M., Arnow, B., Schneider, J. A., Telch, C. F., ... & Kraemer, H. C. (1995). Comparing the cost effectiveness of psychiatric treatments: Bulimia nervosa. *Psychiatry Research*, 58(1), 13-21.

<sup>264</sup> Crow, S. J., Mitchell, J. E., Crosby, R. D., Swanson, S. A., Wonderlich, S., & Lancaster, K. (2009). The cost effectiveness of cognitive behavioral therapy for bulimia nervosa delivered via telemedicine versus face-to-face. *Behaviour research and therapy*, 47(6), 451-453.

<sup>265</sup> Crow, S. J., Agras, W. S., Halmi, K. A., Fairburn, C. G., Mitchell, J. E., & Nyman, J. A. (2013). A cost effectiveness analysis of stepped care treatment for bulimia nervosa. *International Journal of Eating Disorders*, 46(4), 302-307.

<sup>266</sup> Agh, T., Pawaskar, M., Nagy, B., Lachaine, J., & Vokó, Z. (2016). The cost effectiveness of lisdexamfetamine dimesylate for the treatment of binge-eating disorder in the USA. *Clinical drug investigation*, 36(4), 305-312.

<sup>267</sup> Lynch, F. L., Striegel-Moore, R. H., Dickerson, J. F., Perrin, N., DeBar, L., Wilson, G. T., & Kraemer, H. C. (2010). Cost-effectiveness of guided self-help treatment for recurrent binge-eating. *Journal of consulting and clinical psychology*, 78(3), 322-333.

# 7 Conclusions

## 7.1 Cost summary

The total financial costs associated with EDs were estimated to be \$64.7 billion in 2018-19, which equates to \$11,808 per person with an ED. In addition, EDs are also associated with a substantial reduction in wellbeing among people with EDs, which resulted in a further (non-financial) value of \$326.5 billion. These costs are summarized by cost component in Table 7.1.

Some scholars caution against including efficiency losses – the costs associated with the act of taxation and transfers, which distorts incentives and results in inefficiencies in the economy – and argue that they are not valid, but others support their use (see section 4.4). Excluding efficiency losses, the total financial costs would be \$59.9 billion.

Table 7.1: Total costs associated with EDs, 2018-19

Cost component	Total cost (\$bn)	Per person (\$)	Proportion of financial costs (%)
Health system	4,555.4	831	7.0%
Productivity losses	48,634.3	8,874	75.2%
Informal care	6,731.4	1,228	10.4%
Efficiency losses	4,794.8	875	7.4%
<b>Total financial costs</b>	<b>64,716.0</b>	<b>11,808</b>	<b>100.0%</b>
<b>Loss of wellbeing (non-financial)</b>	<b>326,530.2</b>	<b>59,579</b>	

Source: Deloitte Access Economics analysis. Note: components may not sum to totals due to rounding.

Health system costs make up 7.0% of financial costs, accounting for \$4.6 billion, while productivity costs make up the largest share of total financial costs (75.2%). Efficiency losses account for 7.4% of total costs. Informal care accounted for the remaining 10.4% of costs.

It was estimated that individuals bore 29.0% of total financial costs, with the remaining costs shared across government (27.5%), employers (25.2%), society and other payers (11.0%), and family or friends (7.3%).

The value of lost wellbeing due to EDs in the US are also substantial, calculated to total \$326.5 billion in 2018-19. The greatest share of these costs was accounted for by OSFED (35%), followed by BED (30%), AN (18%) and BN (18%), largely reflecting relative prevalence of each condition.

One-way sensitivity analyses were conducted to estimate an upper and lower bound for estimates, including on the mortality, prevalence, health system, productivity, efficiency losses, and VSLY parameters. The upper and lower scenario for these variables was informed based on available estimates published in the literature, such as the published confidence interval or standard error around estimates. In determining on which literature to base these parameter estimates, precedence was given to the primary modelling source employed in this report for each of the high-level cost components. For example, the confidence intervals around SMRs published in Arcelus et al. (2011) were used as a basis for mortality sensitivity parameters.

The results of one-way sensitivity analyses indicated a wide degree of potential variance in the estimates. Under the low case (all parameters were set to their lowest impact) and high case (all parameters were set to their highest impact) scenarios, total financial costs were estimated to range from \$10.6 billion to \$232.8 billion respectively in 2018-19, with the loss of wellbeing value ranging from \$21.8 billion to \$1.4 trillion respectively.

Total financial costs were found to vary most substantially with changes in prevalence, followed by changes in productivity.

Table 7.2: Impact of one-way sensitivity analyses on the social and economic costs of EDs (\$ billions), 2018-19

Sensitivity analysis	Relative variation from base case	Health system	Productivity	Other financial costs	Total financial costs	Loss of wellbeing
<b>High combined</b>	-	9.8	186.1	36.9	232.8	1,442.6
<b>Low combined</b>	-	1.9	5.5	3.2	10.6	21.8
<b>Prevalence</b>						
Upper	198%	8.2	96.3	22.7	127.3	646.8
Lower	40%	2.3	19.6	4.7	26.7	131.8
<b>Mortality</b>						
Upper	166%	4.6	58.4	12.2	75.2	400.5
Lower	76%	4.6	44.6	11.2	60.4	297.0
<b>Health system</b>						
Upper	119%	5.4	48.6	11.6	65.7	326.5
Lower	81%	3.7	48.6	11.4	63.7	326.5
<b>Productivity</b>						
Upper	175%	4.6	84.1	14.2	102.9	326.5
Lower	25%	4.6	17.6	9.1	31.2	326.5
<b>Productivity</b>						
Upper	150%	4.6	72.0	13.3	89.9	326.5
Lower	50%	4.6	27.2	9.9	41.7	326.5
<b>Productivity</b>						
Upper	125%	4.6	60.1	12.4	77.1	326.5
Lower	75%	4.6	37.6	10.7	52.9	326.5
<b>Efficiency losses</b>						
Upper	145%	4.6	48.6	13.7	66.9	326.5
Lower	40%	4.6	48.6	9.6	62.8	326.5
<b>VSLY</b>						
Upper	182%	4.6	48.6	11.5	64.7	593.7
Lower	18.2%	4.6	48.6	11.5	64.7	59.4

Source: Deloitte Access Economics analysis.

## 7.2 Best practice interventions and treatment of EDs

The evidence and modelling described in this report demonstrate that EDs have a huge impact on society. However, more can be done to help reduce the burden of EDs. Based on the available literature, there are a range of effective interventions available to treat EDs. Another primary focus of this report was to summarize evidence pertaining to the cost-effectiveness of stepped care and integrated care models, which are recognized as best practice in the care of people with EDs.

- **Stepped care** is an evidence-based, staged system comprising a hierarchy of interventions, from the least to the most intensive, meaning that treatment is available to meet an individual's needs at the point in time that they require the treatment.
- **Integrated care** is characterized by the comprehensive delivery of health services, designed according to the multidimensional needs of the population and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care.
- Often, there is little distinction between stepped and integrated care models and these are often delivered in tandem in different care settings. However, stepped and integrated care have been separately discussed in this report as they can involve different care settings – for example, stepped care for an individual may include residential care following by an IOP program, while a program delivered solely in an outpatient setting could still be integrated care.

There is limited literature evaluating the cost-effectiveness of the stepped and integrated models of care. Outcomes have been shown to improve with stepped care treatment compared to CBT alone (although it is recognized that CBT is often delivered as a treatment within the context of stepped care), and the time burden upon caregivers diminished substantially. The ICER was \$12,146 per person who abstained from BN behaviors for stepped care and \$20,317 for CBT (delivered alone), suggesting that stepped care may be superior to single step interventions delivered in isolation.

The integrated care model is likely to provide cost-effective treatment by better offering multiple disciplines (e.g. medicine, nutrition, psychology/social work and psychiatry) to support a patient's individual needs and their symptoms. PHPs may also offer significant cost savings compared to inpatient care. In addition, specialist outpatient care may also be superior compared to inpatient treatment (chapter 6).

There are a range of treatments aimed at reducing the burden of EDs, many of which include a psychological or psychotherapy component. Evidence discussed in the literature focused on the effectiveness of: (1) individual therapy; (2) CBT; (3) FBT; (4) hospitalization; (5) internet-based treatment; (6) physical therapy; (7) pharmaceuticals such as antipsychotics; and (8) other complementary therapies. Many of these treatment strategies may improve symptoms of ED, although there is mixed or insufficient evidence outlining how these treatments may impact on the social and economic costs of EDs in the US.

In addition to treatment for known cases of EDs, prevention strategies may be put in place to help people at risk of developing an ED. While a review of prevention strategies was not a primary focus of this report, primary prevention strategies seek to reduce the onset and may involve targeting entire populations (universal) or specific population subgroups or high risk groups (targeted). Secondary prevention seeks to reduce duration or severity of EDs. Further, significant progress has been made in translating ED risk factor research into successful secondary preventive interventions.

### 7.3 Recommendations for future research

This report makes an important contribution to the body of evidence regarding EDs, demonstrating that EDs also impose substantial costs in men and older populations, not only in women and young people. Further, it shows the range of economic costs beyond the direct costs of treatment, including informal caregivers, productivity and broader costs to society. It also values the reduction in wellbeing that occurs due to EDs. This review of evidence and modelling therefore demonstrates (perhaps for the first time) the diversity of EDs both in terms of affected groups, burden to society, and treatments.

However, there are several areas where future research should be undertaken to assist in the prevention and treatment of EDs. For example, there is insufficient evidence regarding EDs of the aging community and the long-term economic costs. This is especially pertinent given the perceptions between EDs being primarily associated with young people.

Moreover, future research is required to understand whether the cost of ED treatment differs by race/ethnicity, gender identity or other important identity groups marginalized by structural

barriers to care, such as by rural residence, disability, or residence in a state without Medicaid expansion. Similarly, further research is required to understand and estimate the additional costs of EDs that may be attributable to structural racism and other structural oppressions in the US.

There is also a need to understand the long-term effects of EDs and the impact of comorbidities on the costs associated with EDs. For example, there is a lack of literature exploring the costs associated with physical and psychological aspects related to EDs. Finally, research is also needed to understand the costs associated with nutritional care for EDs, such as the cost of seeing a dietitian for an ongoing basis.

In part, these gaps in the research may be addressed by improving the quality of data collection, and it is important that nationally representative surveys are enabled to monitor the impact of EDs across the health system, and broader societal costs including productivity and informal care costs.

Another area for future research could be to estimate the costs associated with early intervention or preventable costs of not identifying EDs. For example, social and economic cost savings might be possible through screening, which could identify people with emerging or early EDs in primary healthcare, schools and workplaces who could benefit from early treatment. Screening and early intervention could assist in avoiding the need to access acute care or more structured and intensive care at a later point in time, which would be more costly. Finally, there is also a need to better understand the cost-effectiveness of best practice models of care in the US. New research should continue to focus on the comparative cost-effectiveness of stepped and integrated care.

# Appendix A: Literature review

## A.1. Prevalence and mortality

Table A.1: Prevalence and mortality search terms

Search string	Number of results
("pica"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	52
("avoidant-restrictive food intake disorder"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	13
("other eating disorder"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	4
("binge-eating disorder"[tiab] OR "bulimia nervosa"[tiab] OR "anorexia nervosa"[tiab] OR "OSFED"[tiab] OR "other specified feeding or eating disorder"[tiab] OR "eating disorder"[tiab]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab] OR "duration"[tiab]) AND ("USA"[pl] OR "U.S."[pl] OR "United States"[pl]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	693
((("binge-eating disorder"[tiab] OR "bulimia nervosa"[tiab] OR "anorexia nervosa"[tiab] OR "OSFED"[tiab] OR "other specified feeding or eating disorder"[tiab] OR "eating disorder"[tiab]) AND ("mortality"[tiab] OR "burden"[tiab] OR "disability"[tiab] OR "premature death"[tiab]) AND ("USA"[pl] OR "United States"[pl] OR "U.S."[pl])) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	214
("EDNOS"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	32
("eating disorders not otherwise specified"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	11
("OSFED"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	5
("bulimia nervosa"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	176
("anorexia nervosa"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	229
("binge-eating disorder"[tiab]) AND ("United States"[pl] OR "U.S."[pl] OR "USA"[pl]) AND ("prevalence"[tiab] OR "epidemiology"[tiab] OR "incidence"[tiab]) Filters: Publication date from 2000/01/01 Sort by: [pubsolr12]	126



## A.2. Financial costs

Table A.2: Financial costs search terms

Search number	Search string	Number of results
1	((("binge-eating disorder"[tiab] OR "bulimia nervosa"[tiab] OR "anorexia nervosa"[tiab] OR "OSFED"[tiab] OR "other specified feeding or eating disorder"[tiab] OR "eating disorders not otherwise specified"[tiab] OR "EDNOS"[tiab] OR "eating disorder"[tiab] OR "avoidant-restrictive food intake disorder"[tiab] OR "ARFID"[tiab] OR "Pica"[tiab] OR "rumination-regurgitation disorder"[tiab] OR "feeding disorder"[tiab] OR ("overeating"[tiab] AND "psychological disturbance"[tiab])))	N/A
2	(Search 1) AND ("health"[tiab] OR "utilization"[tiab] OR "physician"[tiab] OR "presentation"[tiab] OR "psychiatrist"[tiab] OR "cost"[tiab] OR "burden"[tiab] OR "treatment"[tiab])	10092
3	(Search 1) AND ("productivity"[tiab] OR "workforce"[tiab] OR "presenteeism"[tiab] OR "absenteeism"[tiab] OR "days off work"[tiab] OR "absence"[tiab] OR "sick days"[tiab] OR "work"[tiab] OR "career"[tiab] OR "society"[tiab])	1397
4	(Search 1) AND ("cost"[tiab] OR "productivity"[tiab] OR "workforce"[tiab])	248
5	(Search 1) AND ("productivity"[tiab] OR "workforce"[tiab] OR "presenteeism"[tiab] OR "absenteeism"[tiab] OR "days off work"[tiab] OR "absence"[tiab] OR "sick days"[tiab] OR "work"[tiab] OR "career"[tiab] OR "society"[tiab]) AND ("USA"[pl] OR "US"[pl] OR "U.S.A"[pl] OR "United States"[tiab]))	23
6	(Search 1) AND ("cost"[tiab] OR "productivity"[tiab] OR "workforce"[tiab]) AND ("USA"[pl] OR "US"[pl] OR "U.S.A"[pl] OR "United States"[tiab]))	8
7	(Search 1) AND ("carer"[tiab] OR "informal care"[tiab] OR "caregiver"[tiab] OR "care costs"[tiab])	119
9	(Search 1) AND ("taxation"[tiab] OR "government"[tiab] OR "DWL"[tiab] OR "deadweight"[tiab] OR "societal"[tiab] OR "lost revenue"[tiab] OR "lost government" [tiab] OR "tax"[tiab])	77

### A.3. Effectiveness and cost-effectiveness of treatment models

Table A.3: Effectiveness and cost-effectiveness of treatment models search terms

Search string	Number of results
("eating disorder" AND "treatment") AND ("stepped-care"[tiab] OR "stepped care"[tiab] OR "integrat* care"[tiab] OR "integrat* pathway*"[tiab] OR "care coordinat*"[tiab] OR "multidisciplinary"[tiab] OR "intervention"[tiab])	400
("eating disorders") AND ("stepped-care"[tiab] OR "stepped care"[tiab] OR "integrat* care"[tiab] OR "integrat* pathway*"[tiab] OR "care coordinat*"[tiab] OR "multidisciplinary"[tiab] OR "intervention"[tiab]) AND ("cost" OR "cost-effectiveness" OR "efficiency" OR "economic evaluation")	63
("eating disorder") AND ("stepped care" OR "integrat* care") AND ("primary care" OR "individual therapy" OR "first diagnosis" OR "outpatient" OR "intensive outpatient" OR "relapse management" OR "complex treatment" OR "treatment plan*")	11
("eating disorder") AND ("stepped care" OR "integrat* care") AND ("primary care" OR "individual therapy" OR "first diagnosis" OR "outpatient" OR "intensive outpatient" OR "relapse management" OR "complex treatment" OR "complex care" OR "treatment plan*" OR "recovery support" OR "medical" OR "medical* instability")	35
("eating disorder") AND ("stepped care" OR "integrat* care") AND ("primary care" OR "individual therapy" OR "first diagnosis" OR "outpatient" OR "intensive outpatient" OR "relapse management")	11

# Limitation of our work

## General use restriction

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