

PAYING THE PRICE

The economic and social impact
of eating disorders in Australia



ACKNOWLEDGEMENT

The Butterfly Foundation acknowledges the valuable input of so many people to this economic and social impact report. Butterfly is committed to an evidence based approach in all its work and convened an Experts Panel to have oversight of the research and development of the report. Each member of that Experts Panel has generously provided their experience, expertise and time. On behalf of all those who will learn and benefit from this report – thank you to our Expert Panel members.

We have also relied on the results of a consultation survey with those with a lived experience. We wish to thank all those who helped in its distribution including members of the National Eating Disorders Collaboration and Richard Kerr from bulimiahelp.org.

Most importantly, our thanks go to each of you with a lived experience of eating disorders. You have provided invaluable insights into the difficult and often very lengthy battle with an eating disorder from the perspective of the individual, the carer, the partner, the family member and the friend.

Thank you for your voice.

Foreword :: Professor Pat McGorry

PAYING THE PRICE - The economic and social impact of eating disorders in Australia

29 November 2012

I welcome this report which, for the first time quantifies the extensive costs of eating disorders in Australia, for both the individual and the wider community.

It reinforces the prevalence and seriousness of these mental illnesses. I believe their debilitating effects are comparable to psychosis and schizophrenia.

The suffering of the individual, their families and the community is greatly magnified by the difficulty many people face in accessing timely and appropriate treatment.

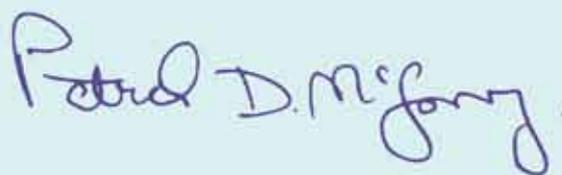
Delays in diagnosis and access to care, exacerbate and prolong the illnesses, costing the community and affected individuals very dearly. The burden of these diseases is at least equal to those of anxiety and depression.

Many eating disorders peak in the teenage years. We are witnessing a tragic waste of personal and economic potential. This report cries out for urgent action. We desperately need a coordinated, government led comprehensive response to this emerging crisis.

I endorse the recommendations of this report including the need for better data monitoring to improve our understanding of eating disorders and new strategies to train our health professionals and provide accessible effective treatment.

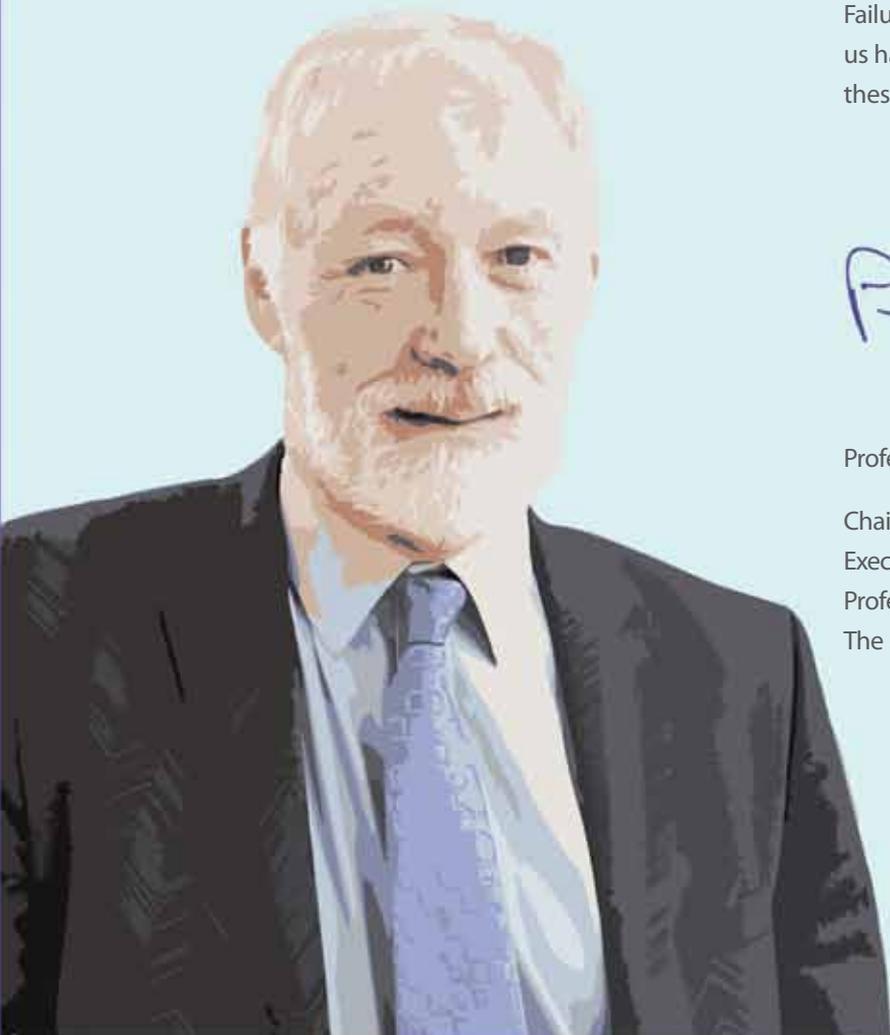
There remains a missing piece - how to prevent eating disorders in the first place? Early intervention is crucial and is dependent on clinicians and services being equipped to recognise and treat an eating disorder before it becomes entrenched and potentially chronic.

Failure to deal with addressing these urgent needs risks us handing to the next generation the full burden of these dreadful illnesses.



Professor Pat McGorry AO

Chair of the National Eating Disorders Collaboration
Executive Director, Orygen Youth Health Research Centre
Professor, Centre for Youth Mental Health,
The University of Melbourne



:: List of acronyms

ABS	<i>Australian Bureau of Statistics</i>
AN	<i>anorexia nervosa</i>
AIHW	<i>Australian Institute of Health and Welfare</i>
AWE	<i>average weekly earnings</i>
BMI	<i>body mass index</i>
BN	<i>bulimia nervosa</i>
BOD	<i>Burden of Disease</i>
BEACH	<i>Bettering the Evaluation and Care of Health</i>
BED	<i>binge eating disorder</i>
COAG	<i>Council of Australian Governments</i>
DAE	<i>Deloitte Access Economics</i>
DALY	<i>disability adjusted life year</i>
DCIS	<i>Disease Costs and Impact Study</i>
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
DWL	<i>deadweight loss</i>
ED	<i>eating disorder</i>
EDNOS	<i>eating disorder not otherwise specified</i>
GP	<i>general practitioner</i>
HOS	<i>Health Omnibus Survey (South Australia)</i>
ICD-10	<i>International Classification of Diseases (Tenth Revision)</i>
ICPC	<i>International Classification of Primary Care</i>
MCPF	<i>marginal cost of public funds</i>
NEDC	<i>National Eating Disorders Collaboration</i>
NHMD	<i>(AIHW) National Hospital Morbidity Database</i>
PIR	<i>Partners In Recovery (program)</i>
PTSD	<i>post traumatic stress disorder</i>
VSL(Y)	<i>value of a statistical life (year)</i>
YLD	<i>years of life lost due to disability</i>
YLL	<i>years of life lost due to premature death</i>

Christine Morgan
CEO
The Butterfly Foundation
103 Alexander Street
Crows Nest NSW 2005

30 November 2012

Dear Christine

Economic and social costs of eating disorders in Australia

Deloitte Access Economics welcomes the opportunity to provide this report on the economic and social costs of eating disorders (EDs) in Australia.

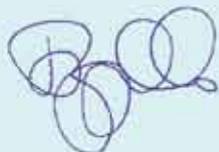
In undertaking the analysis for this study, our personnel have been moved by the experiences of people with eating disorders and by the substantial impacts of these conditions. The extent of impacts was found to be larger than expected, although our methods were conservative.

- We used a combination of international sources for prevalence estimates rather than relying only on the most recent Australian study, which would have provided larger estimates of the number of people with eating disorders had we relied on that source.
- We used the Australian Institute of Health and Welfare (AIHW) estimates of the health system costs of EDs, although these are incomplete (e.g. excluding allied health expenditure) and some ED costs may be coded to other conditions (e.g. anxiety) as EDs are not well understood and there are primary care data coding issues.
- Productivity costs and other financial cost estimates were also conservatively based on the median rather than mean cost reported in survey responses to the community consultation process fielded in October 2012.

We recommend that larger studies are undertaken to triangulate these findings, particularly for productivity and burden of disease impacts, which are based on literature that suggests the severity of impacts from binge eating disorder (BED) and eating disorders not otherwise specified (EDNOS) are similar to the impacts from anorexia nervosa (AN) and bulimia nervosa (BN). That said, comparisons with other conditions such as youth mental illness, anxiety and depression, and obesity, suggest the costs per case of EDs are comparable, which is not unexpected.

We hope that the report assists in raising awareness, prevention and treatment options for people with these serious illnesses.

Yours sincerely,



Lynne Pezzullo
Director, Deloitte Access Economics Pty Ltd
Lead Partner, Health Economics and Social Policy, Deloitte Touche Tohmatsu

Experts :: Panel

The Experts Panel provided oversight of the research and development of this report contributing their expertise in eating disorders, mental health and population health.

PROFESSOR SUSAN PAXTON (CHAIR)

Professor Paxton is currently Professor and Director of Postgraduate Teaching and Learning in the School of Psychological Science at La Trobe University. She is Past President of the Academy for Eating Disorders and of the Australian and New Zealand Academy for Eating Disorders. Professor Paxton is a clinical psychologist and researcher engaged in projects that focus on understanding risk factors of body image and eating problems, evaluating prevention and early intervention strategies and exploring stigma and mental health literacy related to eating disorders in the community.

PROFESSOR PHILLIPA HAY

Professor Hay is Foundation Chair of Mental Health at the School of Medicine, University of Western Sydney and Adjunct Professor of Psychiatry at the School of Medicine, James Cook University and Senior Consultant in Psychiatry at Campbelltown Hospital. She has over 20 years of experience in the field of eating disorders as a clinician, researcher and educator. She is immediate Past-President of the Australian and New Zealand Academy for Eating Disorders (ANZAED) and holds senior committee positions in the Royal Australian and New Zealand College of Psychiatrists (RANZCP) and the International Academy for Eating Disorders (AED). She is regularly invited to give plenary, keynote and other addresses at scientific meetings in Australasia, the Americas and Asia. She is also regularly invited to submit articles and commentaries to Australasian and International journals, publications and books.

PROFESSOR STEPHEN TOUYZ

Professor Touyz is Professor of Clinical Psychology and Honorary Professor in the Discipline of Psychiatry at the University of Sydney. He has written/edited 6 books and over 240 research articles and book chapters on

dieting, eating and eating disorders. He is a fellow of the Academy of Eating Disorders (AED) and the Australian Psychological Society (APS). Professor Touyz is a past president of the Eating Disorders Research Society (EDRS). He was the inaugural treasurer of the Australian and New Zealand Academy of Eating Disorders (ANZAED). He has also served on the Executive of the Eating Disorder Foundation of New South Wales and is a member of the Editorial Board of the European Eating Disorders Review. He is the co-editor of the Journal of Eating Disorders and was recently presented with a Leadership Award in Research by the Academy of Eating Disorders.

PROFESSOR DAVID FORBES

Professor Forbes is an academic paediatrician with training in clinical nutrition and gastroenterology. He is based in the School of Paediatrics and Child Health at the University of Western Australia, and at Princess Margaret Hospital for Children in Perth, where he has been part of the Eating Disorders Program since 1996, and provides clinical leadership in the care of young people with eating disorders. He has a strong interest in health advocacy and policy development

DR SLOANE MADDEN

Dr Madden is nationally and internationally recognised for his expertise in the treatment and management of eating disorders. He is co-director of The Eating Disorder Service of the Sydney Children's Hospital Network, the largest public eating disorder service in NSW and one of the two largest adolescent eating disorder services in Australia. Dr Madden's research has three major foci, early onset eating disorders, the treatment of anorexia nervosa and the neurobiology of eating disorders. Dr Madden was the lead investigator in an Australia wide study exploring the eating disorders in children under the age of 13 years and is a chief investigator and the clinical coordinator of a current, NHMRC funded, inpatient treatment trial of adolescent anorexia nervosa. Dr Madden is the chair of the neuroimaging special interest group in the Academy of Eating Disorders (AED).

He has been invited to present keynote addresses symposia and discussion panels on this subject at both local and international meetings. Dr Madden is the author of over 30 peer reviewed journal articles and book chapters on eating disorders.

PROFESSOR FEDERICO GIROSI

Federico Girosi has been an Associate Professor in Population Health at the School of Medicine, University of Western Sydney, since late 2011. He is currently an investigator in a project that utilizes linked data to investigate geographic variations in primary care and he is developing a microsimulation model to predict the health and health care utilization trajectories of the New South Wales population of age 45 and older. Dr. Girosi earned a Ph.D. in Health Policy from Harvard University in June 2003, and worked 8 years at the RAND Corporation (Santa Monica, U.S.A.) as a health economist and modeller. At RAND he was the leader of the modelling team that developed the COMPARE microsimulation for the analysis of health insurance reform. He was also involved in the development of the Future of the Elderly Model (FEM), a model that can be used to study the costs and benefits of prevention for the U.S. population over age 51. Dr. Girosi also led the modelling effort for a Gates Foundation project aiming to evaluate the benefits of introducing new diagnostic tools in the developing world. In addition, he was part of a RAND team that quantified the cost and benefits of widespread adoption of electronic medical records systems in health care. He also holds a Ph.D. in Physics from the University of Genoa, Italy, and conducted research for 10 years at the Artificial Intelligence Laboratory, at the Massachusetts Institute of Technology, in the fields of statistical data analysis and computer vision.

ANNE DOHERTY

Anne has over thirty years experience in health, the majority spent in mental health. Anne spent 12 years in forensic mental health in New South Wales. She is committed to improving patient/consumer care and the patient/consumer and carer experience. Anne currently holds the position of Executive Director Mental Health, Southern Health Victoria.

LESLEY COOK

Lesley established Partners in Practice as the health and welfare arm of Blackboro Associates Pty Ltd consulting services in 2007 after a career that has encompassed all areas of community welfare. With over 30 years experience working in and with community organisations, Lesley's areas of expertise include knowledge management, partnership brokerage, social inquiry and stakeholder consultation, project design, and evaluation. Her area of specialisation is the facilitation of collaboration and she has worked with the National Eating Disorders Collaboration since its inception in 2009.

CHRISTINE MORGAN

Christine is the CEO of the Butterfly Foundation and National Director of the National Eating Disorders Collaboration. Prior to her role with Butterfly, Christine was General Manager with Wesley Mission, responsible for the Community Services and Corporate Services portfolios. Christine has qualifications in law and business and prior to entering the not for profit sector in 2005 served in senior executive corporate roles for over 20 years, holding the positions of General Counsel / Company Secretary for a number of listed public companies on the ASX 200.

About :: Butterfly Foundation

The Butterfly Foundation represents all people affected by eating disorders – sufferers, their families and their friends. As a leading national voice in supporting their needs, Butterfly highlights the realities of seeking treatment for recovery, and advocates for improved services from both government and independent sources.

Butterfly operates a national helpline, which is staffed by counselors experienced in assisting with eating disorders. It also provides a wide range of facilities for service providers and recovery groups.

Because Butterfly recognises that eating disorders often arise from poor body image, it delivers a range of Positive Body Image workshops to schools and workplaces through its education program. It has a strong media presence to raise awareness of Butterfly's perspective in community debates about body image and eating disorders.

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Throughout its work Butterfly emphasises the critical importance of prevention and early intervention strategies in limiting the development of, and suffering from, negative body image and eating disorders. To expand knowledge in this field. The Butterfly Research Institute supports academic research projects and funds PhD research scholarships.

Butterfly is committed to collaboration across the sector and works with allied medical and mental health providers as well as with clinicians and academics. Butterfly has been appointed to co-ordinate the National Eating Disorder Collaboration (NEDC) for the Australian Department of Health and Ageing.

For help and information please call the national support-line on 1800 33 4673 (ED HOPE)

www.thebutterflyfoundation.org.au

Everyone should have access to support .

It is NOT FAIR that many, many people cannot access this type of care due to cost.



Executive :: Summary

Unfortunately, as this illness often presents itself in the teen years, the behaviour can be mistaken with 'puberty blues'. And then one day you realise that it is not puberty - there is something very wrong.

By then your child is very ill.



There are more than 913,000 people in Australia with eating disorders in 2012. The total socio economic cost of eating disorders in 2012 is \$69.7 billion.

In 2012 Deloitte Access Economics was commissioned by the Butterfly Foundation to examine the economic and social costs of eating disorders in Australia. This review was supported by an advisory panel of experts in eating disorders, mental health, and population health.

Prevalence of eating disorders and associated mortality

The last official estimate by the Australian Institute for Health and Welfare (AIHW) suggested that there were 23,464 people with eating disorders in Australia in 2003 (Begg et al, 2007).

- This estimate was not based on Australian data, but mainly on a relatively small survey of Swiss schoolgirls in the mid-1990s.
- The AIHW estimate also only covers two eating disorders, anorexia nervosa (AN) (male and female) and bulimia nervosa (BN) (only female estimates). No estimates were made for Binge Eating Disorder (BED) or Eating Disorder Not Otherwise Specified (EDNOS), which have higher prevalence than AN and BN.
- As the Australian Bureau of Statistics (ABS) does not appear to have ever collected data on eating disorders, the AIHW figure remains the only official Australian estimate.

Recent population based surveys in South Australia, New Zealand and the United States yield far higher (although widely varying) estimates. Taking an average

of these studies, Deloitte Access Economics estimates that there are 913,986 people in Australia with eating disorders in 2012, or around 4% of the population (Table i). Of these people, 3% have AN, 12% BN, 47% binge eating disorder and 38% other eating disorders. Females comprise around 64% of the total.

- This estimate may be conservative, as it is lower than the only Australian study (Hay et al, 2008), which also found that the rate of disordered eating behaviour had doubled in the ten years to 2005.

The imbalance between reported estimates of mortality from eating disorders and evidence from scientific studies is also substantial. The ABS (2012) indicates a total of 14 deaths from eating disorders in 2010. However, the latest meta-analysis of epidemiological studies from the published literature (the gold standard of health research) indicates that mortality rates are almost twice as high for people with eating disorders and 5.86 times higher for people with AN (Arcelus et al, 2011), compared to those without the conditions. On this basis there were an estimated 1,829 deaths from eating disorders in 2012.

Cost impacts of eating disorders

The AIHW reports health system expenditure for eating disorders of \$80.4 million in 2008-09. Inflating this to allow for subsequent prevalence increase and health cost inflation suggest expenditure of \$99.9 million by 2012.

Table i : Estimated prevalence of eating disorders, 2012

	Anorexia	Bulimia	BED	EDNOS	Total
Females	18,284	78,154	264,516	219,667	580,621
Male	7,469	29,761	164,317	131,818	333,365
Total	25,753	107,915	428,833	351,485	913,986

Executive Summary

Table ii : Total ED costs, by type and bearer, 2012 (\$m)

	Individual	Family /Friends	Federal Govt	State Govt	Employers	Society /Other	Total
Health system costs	10.4	7.9	42.6	26.4	0.0	12.6	99.9
Productivity costs	9,378.1	0.0	4,841.9	0.0	843.0	0.0	15,063.0
Carer costs	0.0	5.7	2.8	0.0	0.0	0.0	8.5
Other financial costs	585.2	8.8	0.0	0.0	0.0	0.0	594.0
Deadweight losses (DWLs)*	0.0	0.0	0.0	0.0	0.0	1,414.8	1,414.8
Transfers	0.0	-7.2	7.2	0.0	0.0	0.0	0.0
Total financial	9,973.8	15.2	4,894.6	26.4	843.0	1,427.4	17,180.2
BoD	52,554.9	0.0	0.0	0.0	0.0	0.0	52,554.9
Total with BoD	62,528.7	15.2	4,894.6	26.4	843.0	1,427.4	69,735.2

* DWLs measure the administrative and efficiency impacts of levying taxation to fund government payments.

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The productivity impacts of eating disorders were estimated as \$15.1 billion in 2012, similar to the productivity impacts of anxiety and depression which were \$17.9 billion in 2010 (Access Economics, 2010). Of this cost, \$2.0 billion is due to lost lifetime earnings for young people who die. Eating disorders also have lengthy duration – an average of around 15 years in survey respondents – which can mean long lasting productivity impacts for those living with eating disorders, such as lower employment participation (costing \$6.0 billion) and greater absenteeism (\$1.8 billion) and presenteeism (\$5.3 billion). Productivity costs are borne largely by individuals, but also by Federal Government (in the form of less taxation revenue) and by employers (sick leave and lower productivity from presenteeism). Table ii also provides estimates of the cost of informal care for people with eating disorders, totalling \$8.5 million, based on data from the Federal Department of Human Services, and other financial costs of \$594 million, based on survey data for out-of-pocket expenses borne by people with eating disorders and their families and carers.

The “burden of disease” from eating disorders is estimated as \$52.6 billion, calculated by multiplying the years of healthy life lost (measured in disability adjusted life years or DALYS), by the value of a statistical life year (VSLY) as recommended by the Department of Finance

and Deregulation. The estimate is comparable, although slightly larger, than the estimated value of the burden of disease for anxiety and depression of \$41.2 billion (Access Economics, 2010).

Recommendations – data and monitoring

A pressing need in relation to eating disorders is collecting better information, particularly in relation to tracking prevalence, mortality and health system costs, and better defining less well known eating disorders. While AN and BN are well defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), EDNOS is composed of disparate criteria. One of these – BED – is the most common single ED, and in early 2013 will be classified independently in the DSM 5. Almost half (44%) of people with BED are severely obese (Spitzer et al, 1993), and it is probable that many of these people may currently have their treatment classified as “consequences of obesity” rather than BED.

Deloitte Access Economics makes the following recommendations regarding information.

- **Include eating disorder questions in the Australian Health Survey.** New Zealand and the United States include validated questions about eating disorders in their equivalent to our Australian Health Survey. It would be relatively simple and

inexpensive to do the same. However, self-reported data are not as reliable as epidemiological data, and an Australian epidemiological study would be very valuable to better understand eating disorders and their impacts nationally. EDs should be recognised as a serious psychiatric disorder.

- **Reassess mortality data.** The AIHW (2012) notes that most people have three causes of death, and as many have five causes of death (20%) as have only one. If eating disorders have the mortality rates that the literature suggests it is important to verify this, which would also be assisted by funding a national epidemiological study.
- **Include BED as a condition in the International Classification of Primary Care.** The ICPC 2 Plus is an Australian categorisation system used by the AIHW to measure non-hospital treatment by disease type. At present, it contains categories for AN and BN, but not for BED. Once the DSM 5 has been released, there may be merit in reviewing the inclusion of BED in the ICPC2. It is possible that the small reported non-hospital costs for eating disorders other than AN and BN may be partly due to general practitioners (GPs) having limited awareness of BED and classify it by its frequent impact (overweight and obesity) instead.
- **Include eating disorders in welfare data.** At present, there is no information on eating disorders as a cause for unemployment benefits, sickness benefits or disability support pension. Given the high prevalence of eating disorders, this should be revisited.

Treatment recommendations

Relative to prevalence, there appears a lack of focus on treatment for eating disorders across acute and community care settings. The reports from survey participants of not being able to access appropriate treatment when needed are harrowing.

- **Make eating disorders a priority for Medicare Locals.** Medicare Locals are a commendable recent

initiative by Council of Australian Governments (COAG) to better coordinate primary health care. They have been explicitly tasked with improving the patient journey, mapping population health needs and identifying services gaps. Medicare Locals have somewhat of an initial focus on preventative health and diabetes, which is relevant given the interface between BED, obesity and diabetes. Early intervention for people with eating disorders is paramount. Medicare Locals may be able to help primary providers enhance identification of people with early symptoms of eating disorders, and conduits for appropriate care.

- **Increase Medicare psychology coverage and/or Partners In Recovery (PIR) referral.** Many survey respondents noted that they often require psychiatric visits on a weekly basis, but noted that Medicare coverage is capped at ten visits per year, when the literature suggests a minimum of twenty visits per annum is required to be effective. Given the high productivity costs of eating disorders – and thus lost taxation revenue – it is possible that increasing the visit cap may have little adverse impact on the net Commonwealth budget position. Alternatively, if the cap is approached, referral into the PIR program may be appropriate for those where symptoms are severe and persistent.
- **Increase private health insurance coverage.** Judging from survey participant feedback, private health insurance appeared to be necessary but insufficient. Participants were grateful that their insurance covered most of their hospital costs, but also noted that it failed to cover a majority of their other costs, or left large out-of-pocket ‘cost gaps’ between what was reimbursed and actual fees (GPs, counselling, dietitians, etc). Given eating disorders are long-lasting and complex to treat, it would help people if such multidisciplinary costs could be covered by insurance, although it is acknowledged premiums may have to increase to cover this.

Deloitte Access Economics

¹ Deloitte Access Economics ran a small survey designed to measure out of pocket costs for people with eating disorders, which suggested higher health system costs. However, in the interests of conservatism and using official estimates where robust, the AIHW figures were adopted in this report.

LIMITATION OF OUR WORK

General use restriction

This report is prepared solely for the internal use of The Butterfly Foundation. This report is not intended to and should not be used or relied upon by anyone else and we accept no duty of care to any other person or entity. The report has been prepared for the purpose of estimating the economic and social cost of eating disorders in Australia. You should not refer to or use our name or the advice for any other purpose.



Butterfly

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