



NATIONAL MENTAL HEALTH RESEARCH STRATEGY

BACKGROUND PAPER: Eating disorders (Session 4A)

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Background

Around 15% of Australian girls will experience an eating disorder (ED) by the time they are 19 years of age;^{1,2} disordered eating (DE) affects 23% of young Australian women with long-term detrimental impacts on physical and mental quality of life.³ Males account for one in four cases of anorexia nervosa and bulimia nervosa,⁴ and males account for approximately one third of community adults reporting DE in Australia.⁵

EDs carry the highest mortality of any psychiatric disorder.^{6,7} They are associated with higher rates of medical problems including diabetes, hypertension and dyslipidaemia independent of obesity and co-occurring psychiatric disorders.⁸ EDs in adolescence lead to increased risk of poor mental health in early adulthood, including: substance use, deliberate self-harm, suicide attempts, and depressive and anxiety disorders; as well as a range of serious medical problems: cardiovascular symptoms, chronic fatigue, chronic pain, osteoporosis, infectious diseases, neurological symptoms, and adverse weight outcomes (high-weight for Bulimia Nervosa and Binge ED, low-weight for Anorexia Nervosa).^{9,10} In 2012, 913,000 Australians were estimated to be currently experiencing an ED at a socioeconomic cost of \$69.7 billion.¹¹

Longer duration of an ED has an adverse impact on treatment outcome.¹² Time from the development of symptoms to presentation for treatment, however, is more than 8 months for children and adolescents,¹³ and 5 to 6 years in young adults.¹⁴ Only 25% of people with an ED seek treatment.^{15,16} Many adolescents and their families report considerable barriers to receiving timely and appropriate diagnosis and treatment,¹⁷ including lack of recognition in primary health-care settings with less than one-third of bulimia nervosa cases detected by health care professionals.¹⁸

In the absence of adequate early detection and intervention, current outpatient treatments in tertiary settings only assist around 28% to 49% to full remission of symptoms: even treatments with the strongest evidence base are unable to achieve better remission rates. For instance, between 22% and 42% of children with anorexia nervosa receiving Family Based Treatment have poor outcome at 12-month follow-up;^{19,20} only 33% of people with Bulimia Nervosa and Binge ED are remitted at end of outpatient cognitive behaviour therapy;²¹ network meta-analysis shows us that manualised outpatient treatments for adult Anorexia Nervosa are no more effective than Specialist Supportive Clinical Management,²² with only 28% remission at 12-month follow-up.²³

Research to date

Over the last 30 years, the focus of research has been in the broad areas of epidemiology, risk factors, and interventions (prevention and treatment), with substantial progress and agreement reached in the following areas:

1. We have moved from seeing EDs as being caused by families to a result of the complex interplay of genetic and (primarily) non-shared environmental influences, with genetic influences accounting for an average of 52% of the variance.²⁴
2. Diagnoses have been expanded from anorexia nervosa and bulimia nervosa to include Binge ED, Other¹ and Unspecified² Specified Feeding and ED, and Avoidant and Restrictive Food Intake Disorder.
3. The dominance of diagnostic criteria has decreased given people with DE experience similar levels of impairment to those with EDs. Widely adopted definitions of outcome utilise a continuous measure of DE, linked with body mass index and behavioural indices.²³
4. A variety of evidence-based guidelines for interventions now exist.²⁵
5. We have identified universal and selected prevention approaches which can protect against the development of an ED.²⁶

Gaps and strategic goals

As a field, we have identified the stuck points and unknowns that prevent us from making rapid progress in meaningful improvements in our evidence-based interventions (EBI). A Delphi consensus study²⁷ conducted in 2019 with 291 members of the Australia and New Zealand Academy for EDs and the National EDs Collaboration asked participants to identify research priorities in EDs. Three panels were formed: Consumers and Carers (n=109, 37%), ED Specialists (n=103, 35%, clinicians and researchers), and Affiliates (n=53, 18%, non-specialists). Endorsed items had to be rated as 'Essential' or 'Important' by at least 80% of each of the three panels. Twenty-two items addressing translation, dissemination and implementation reached consensus across five areas, summarised below as *identified gaps* (in bold) followed by *potential strategic goals* under five general themes.

Ensuring our EBI are suitable for those who need them

In 2018, the Australian Institute of Health and Welfare reported a gap in EDs with respect to a "*lack of nationally consistent data on eating disorders, especially prevalence, estimated costs to society, and service access*".²⁸ All epidemiological studies to date underestimate ED prevalence as they have failed to assess the most common EDs and frequently excluded males.²⁹ We also require a better understanding of risk factors, their interactions and relative importance in the crafting of more effective complex interventions.³⁰

1. ***National dataset***: Generate the first nationally representative data on the prevalence and incidence of EDs, burden of disease, health-related quality of life, treatment-seeking and pathways through care; Draw together existing datasets on EDs; Integrate the assessment of EDs or their precursors into existing large national surveys; Collaborate with industry or health services to gather data on the incidence and prevalence of EDs from their customers or users; Sample under-studied groups and diagnoses. Examine flexible diagnostic criteria to detect where meaningful differences exist.
2. ***EDs across the lifespan***: Determine how different milestones across the lifespan (e.g., puberty in boys and girls, mid-life changes associated with pregnancy/parenting, menopause or ageing across men and women) potentiate risk for the development of body dissatisfaction and DE.

3. *Critical risk factors:* Evaluate and compare more recently emerging factors such as: biomarkers, apart from body mass index, that more accurately tell us when an ED is developing; the role of social media, including weight stigma and appearance-based teasing among children; common explanatory factors between self-harm and EDs; macro-level pressures that place vulnerable individuals at risk (e.g., laws, policies, curriculum, commercial industry practices); the role that obesity policy/interventions may play in the rise in prevalence of DE and the presentation for tertiary treatments in younger children.

Getting people EBI earlier

Early detection and early intervention are key to ensuring people have a better chance of recovery.

1. *Integrated prevention programs:* Use an implementation science paradigm to explore the efficacy of combined mental health and EDs prevention approaches. Develop a better understanding of how obesity prevention might contribute to poor mental health or ED risk (e.g., by increasing body dissatisfaction, DE, weight cycling, weight stigma, depression or EDs), and whether ED specialists that are fully integrated into obesity policy, intervention and research can achieve better health outcomes.
2. *Early detection in primary care:* Having GPs ask about mental health (as opposed to eating or dieting) is the best explanatory variable for receiving treatment from a mental health specialist for people with non-underweight EDs.³¹ Systematic ways to achieve increased assessment by primary healthcare providers that leads to appropriate treatment referral is required, along with investigation of how it changes ED outcomes (including health economics).
3. *Early intervention approaches at all critical risk periods:* Not only is there a paucity of early intervention approaches in EDs,³² but those few that do exist require enhancing and more rigorous evaluation, especially in primary health settings. This was rated as the top item in the Delphi study.
4. *Reducing impact of stigma:* Mental-health related stigma reduces help-seeking,³³ and weight stigma can trigger physiological and behavioural changes linked to poor metabolic health and increased weight gain.³⁴ Ways to reduce the impact of stigma on detection and timely and appropriate treatment provision is required. Information for use in large-scale public health interventions that can reduce stigma^{35,36} and the impact on treatment seeking, require investigation.

Ensure EBI are provided in real-world settings

The research-practice gap (dissemination of EBI from controlled research environments to routine clinical care or community settings) is widely recognised as problematic.³⁷ This can be caused because EBIs are unsuited to diverse audiences, economically inefficient and unscalable to the population level. Treatment setting gaps can arise by choosing not to provide an EBI,^{38,39} not competently delivering an EBI,⁴⁰ or deliberately omitting effective elements of an EBI.^{41,42,43} Addressing the research-practice gap should be considered in the context of the suboptimal responses to current EBI, and the so-called “three-legged stool” of evidence-based practice in ED treatment:⁴⁴ research evidence, clinical expertise, and consideration of the intended participants’ characteristics, values, and circumstances.

We know little about the extent and nature of the research-practice gaps, and how to address these. We require information on prevention services being provided across health/education settings and how these might be integrated with other health promotion practices. The recent expansion of Medicare items for

severe EDs requires us to ensure that public money is being used wisely and to the greatest benefit of consumers.

How to deliver EBI to more people

“Accessible evidence-based treatment” was the fourth highest rated item in the Delphi study.

1. *The role of non-specialists in delivery of early identification and early intervention programs:* Analysis of the impact on treatment costs and outcomes is required, with training and utilisation of local community workers, lay people, recovered peer workers, primary health practitioners or interns.
2. *Innovative treatment platforms:* Evaluation is required of the role of tele- or digital health with varying levels of support that minimises barriers of geography, disability, travel, finances and interpretation, and the extent to which it engages people and the types of outcomes that can be achieved.
3. *Better support for families and carers in providing key elements of treatment:* Current frontline treatments for children and adolescents rely on families’ close and extended involvement in meal support, symptom interruption and emotion coaching to achieve full and sustained recovery. This is a huge burden for families and often requires temporary removal from the workforce, which is not financially viable for all. Research needs to explore if there are less burdensome approaches to the inclusion of families in providing and enhancing treatment.
4. *Alternatives for children and adolescents whose family cannot be involved as partners in treatment:* There is currently a poor level of evidence for any other treatments for children and adolescents not involving families. This is a major gap that needs to be addressed to significantly reduce burden.
5. *Interventions for carers:* While Australia has an active culture of providing and evaluating skills-based interventions and support with carers, new innovations in this area are required.
6. *Implementation research of prevention and early intervention programs:* These require further enhancement and embedding within existing services for efficient population-level dissemination (i.e., in a way that is feasible for schools, universities, child health clinics or kindergartens, and primary health services to adopt them). We have existing EBIs developed by Australian researchers that could be effectively implemented in perinatal and primary health services, preschool (early years), primary, secondary and tertiary education settings, and during midlife via online, social media or workforce environments. Implementation research showing program efficacy, and the barriers and facilitators to successful adoption, remains a clear gap in the field.
7. *Approaches that meet the needs of Aboriginal and Torres Strait Islander peoples:* to date just one publication on DE in Indigenous Australians exists, showing it to be as common as in non-Indigenous peoples.⁴⁵ We know nothing about effective strategies to treat DE.

New approaches for those people with EDs for whom current EBI do not lead to recovery

“What to do when first line treatments don’t work” and “enhancing existing ED treatments” were the second and third highest rated items in the Delphi study. In the only other comparable study of research priorities involving patients, carers, researchers and clinicians, seven of the top ten priorities also related to improved treatment.⁴⁶ Addressing our suboptimal remission rates with new and innovative treatments and augmentation of existing treatments with uniform evaluation⁴⁷ is an urgent and major focus.

1. *Person-centred collaborative care*: Issues for further investigation include matching treatments to profiles; use of flexible treatment protocols depending on progress in EBI; the adjunct role of recovered peer workers; implementation of evidence-based suicide prevention programs among individuals either at high-risk of an ED, currently receiving treatment, or experiencing a chronic illness trajectory.
2. *Integrated care*: Canada and Europe highlight transition from child/youth to adult services as a priority.^{48,49} Treatment transitions between services are often disjointed and difficult for the patient and their caregivers to navigate, with marked contrast in the degree of involvement of the family. The two-system model does not suit a disorder where the peak age of onset is 15–25 years and the average duration of illness is 6 years. New approaches are needed.
3. *The definition and support of recovery*: We need to develop a uniform definition that incorporates the patient perspective, with 54% of people with lived experience considering themselves recovered while not meeting an objective definition of recovery.⁵⁰

Challenges

The main reasons for the gaps in current knowledge include:

1. Misperception and stigma: EDs are misperceived as rare disorders of low impact, further trivialised as illnesses of vanity in a population that will ultimately “grow out of it”.
2. Ambivalence: Weight stigma is widely sanctioned in obesity, and EDs are one of the only mental health disorders where it is not uncommon for people to say “I could do with a little bit of anorexia nervosa” and health professionals to say “you are not thin enough for an ED”. Societal sanctioning of appearance monitoring, and an extreme dieting and exercise culture, results in less impetus to address EDs.
3. Lack of accurate data on epidemiology and burden: This has entrenched misrepresentations and ambivalence, leading to poor ED mental health literacy throughout Australia.
4. EDs have been ignored by decision-making sectors (i.e., policy makers and grant reviewers): EDs were excluded from the 2013–2014 replication of the adolescent national survey and have never been included in the adult Australian national mental health surveys. EDs had not made the inclusion list for any previous Australian national mental health plan until the Federal Minister for Health, Greg Hunt directed that they be included among populations requiring specific consideration in the [2017 Fifth National Mental Health and Suicide Prevention Plan](#).
5. Lack of integration with wider mental health sectors: This has resulted in inadequate collaboration with other sectors of mental health research, despite the overlap in comorbid conditions with EDs, including elevated suicidality.
6. Past reliance on diagnostic criteria: Previous diagnostic criteria has severely limited research and impact because of rigid criteria that most people with EDs do not fit, meaning participants can be hard to find and research is under powered.
7. Obesity is considered a greater priority in medical research funding and may in turn be promoting DE. Obesity researchers may be reluctant to collaborate with the ED field because of the concerns we raise about harm caused by interventions that focus on weight loss and neglect the major mental health issues experienced by people with a high BMI.

8. The ego-syntonic nature of some EDs leads to denial and minimisation resulting in a reluctance to participate in research, especially treatment studies. Consequently, participation is associated with high dropout rates. The complex interplay between physical and mental symptoms is particularly marked for EDs compared to other mental disorders.

As a result of all these factors, despite their huge burden, EDs have had less research funding than all other mental disorders in Australia.⁵¹ Government funding for ED research equates to approximately \$1.10 per affected individual, which stands in marked contrast to commensurate research funding for autism (\$32.62) and schizophrenia (\$67.36). EDs are considered a lower priority for funding among national medical research funding bodies than many other mental health conditions, with less investment in capacity building. This has contributed to a lack of co-ordinated leadership across the field in Australia.

Opportunities

Our opportunities to ensure alignment between research and the needs of practitioners and the needs of consumer and carers include:

1. The National EDs Collaboration (NEDC): Continuously supported by the Federal Department of Health and Ageing for 10 years, the NEDC is a collaboration of people and organisations with an expertise in, and/or lived experience of, EDs. The vision is threefold: (1) EDs are a priority mainstream health issue in Australia; (2) a healthy, diverse and inclusive Australian society acts to prevent EDs; (3) every Australian at risk has access to an effective continuum of EBI. The NEDC has completed numerous projects informing the development of appropriate policies and systems related to EDs e.g., work force development, primary health network capacity building and implementation of the National EDs Framework.
2. The Australia and New Zealand Academy for EDs (ANZAED): This is the peak body representing EDs, bringing together the collective expertise of ED researchers, clinicians and public health workers to improve our Nation's capacity to grow knowledge and provide a continuum of care for people with EDs.
3. Expansion of Medicare items for severe EDs: In this context, the Sunshine Coast EDs Access Trial, which seeks to improve access to evidence-based multidisciplinary treatment for people with EDs living in that region, was funded by the Federal Government. Additionally, the NEDC and ANZAED have been asked to establish a voluntary credentialing process for clinicians using ED MBS items.
4. A clinical registry: The TrEAT project, developed in 2016, involves data collection across outpatient and day program ED centres in NSW, QLD, WA and NZ. The registry aims to standardise quality assurance evaluation across centres and provision of information to governments to inform resource allocation. It also gives access to a large database of a difficult to recruit clinical population. This facilitates research using an implementation science paradigm to improve understanding of ED treatment and outcomes in real-world settings, access to and pathways through care, as well as social and economic costs (e.g., through data linkage). With funding, the registry can expand its operations.
5. The ED research field in Australia is recognised internationally for its strength, breadth and innovation. Australia is a world leader in prevention research, with the development of a variety of EBI that can significantly reduce the burden of EDs. As a field, we have huge capacity and passion to provide insights into transdiagnostic mental health interventions, with specialist understanding

of body image, nutrition, exercise, physiology, a wide range of mental health issues, and development and testing of complex interventions.

Conclusion

We see the most critical enabler of future research to be an integrated transdisciplinary approach that provides revolutionary solutions to the issues outlined above. While we have the InsideOut Institute at the University of Sydney, which focuses on the clinical practice nexus, we require the funding of Centres of Research Excellence that integrate expertise across Australia. These centres would involve consortia of universities, research institutes, NGOs, people with lived experience and industries across the epidemiology, aetiology, prevention and clinical practice integration, with a focus on capacity building. These centres would capitalise on the overlap of concerns and interests of mental health and obesity researchers, such as shared risk and protective factors that can inform development of better interventions.⁵² There is agreement across researchers, clinicians and those with lived experience about the research gaps and approaches to addressing these. With strategically delivered funding, we have ability to lead international research efforts in EDs.

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