Australian Eating Disorders Research & Translation Strategy 2021-2031

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The University of Sydney, Sydney, Australia.

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Lived Experience Research Advisory Group

Bronny Carroll
Lexi Crouch
Kelly Griffin
Amanda Long
Sophie Smith

Australian Eating Disorders Research Collaboration

Phillip Aouad
Robert Boakes
Leah Brennan
Emma Bryant
Susan Byrne
David Castle
Ian Caterson
Lyn Chiem
Simon Clarke
Janet Conti
Gen Dammery
Jasmine Fardouly
Nasim Foroughi
Mathew Fuller-Tyszkiewicz
Anthea Fursland
Veronica Gonzalez-Arce
Bethanie Gouldthorp
Scott Griffiths
Amy Hannigan
Laura Hart
Mel Hart
Susan Hart
Phillipa Hay
Ross King
Michael Kohn
Eyza Koreshe
Isabel Krug
Jake Linardon
Randall Long
Sian McLean
Sloane Madden
Sarah Maguire
Jane Miskovic-Wheatley
Deborah Mitchison
Jonathon Mond
Richard O'Kearney
Roger Patterson
Susan Paxton
Genevieve Pepin
Andrea Phillipou
Rebecca Pinkus
Bronwyn Raykos
Paul Rhodes
Elizabeth Rieger
Janice Russell
Fiona Salter
Susan Sawyer
Urvashnee Singh
Evelyn Smith
Marika Tiggemann
Stephen Touyz
Lenny Vartanian
Tracey Wade
Andrew Wallace
Warren Ward
Sarah Wells
Eleanor Wertheim
Simon Wilksch

Advisory Committee
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Stephen Touyz – Co-Chair
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Shannon Calvert
Ian Hickie
Francis Kay-Lambkin
Sian McLean
Thy Meddick
Susan Paxton
Genevieve Pepin
Judith Piccone/Karen Rockett
Beth Shelton
Sarah Squire/Juliette Thomson/
Ranjani Utpala
Michelle Williams

Australian Government Department of Health
Eleanor Bruyn
Lauren Hendriks
Kate Humphreys
Sarah Syme
Marricel Velasquez
Rebecca Wacholcz

Project Team
Claire Aird
Phillip Aouad
Emma Bryant
Jennifer Burrows
Juanita Nantes
Sarah Maguire
Danielle Maloney
Peta Marks
Jane Miskovic-Wheatley
Stephen Touyz

Research & Translation experts:

Professor Maree Teesson, Director of the Matilda Centre for Research in Mental Health and Substance Use; Robyn Mildon, Executive Director of the Centre for Evidence and Implementation; Dr Anthony Filippis, Chief Executive Officer Managing Director of Neurosciences Victoria; Professor Ian Hickie, Professor of Psychiatry Translational Research Collective and Co-Director, Health and Policy, Brain and Mind Centre The University of Sydney; Maureen Lewis Chief Executive Officer and Sarah McNeill Assistant Director, National Mental Health Commission.

Organisations involved in consultation:

National Eating Disorder Organisations: Australia & New Zealand Academy for Eating Disorders (ANZAED), Butterfly Foundation (Butterfly), Eating Disorders Families Australia (EDFA), InsideOut Institute (IOI), National Eating Disorders Collaboration (NEDC).

State and Territory Eating Disorder Organisations: Carers ACT, Eating Disorders Program ACT (EDP ACT), InsideOut Institute (IOI), Eating Disorders Victoria (EDV), endED, Centre of Excellence in Eating Disorders (CEED), Queensland Eating Disorder Service (QuEDs), South Australia Statewide Eating Disorder Service (SEDS), Eating Disorders Queensland (EDQ), Western Australian Eating Disorders Outreach & Consultation Service (WAEDOCS), Centre for Clinical Interventions WA (CCI).

State and Territory:

ACT: ACT Eating Disorders Health Care Services, Canberra Health, Office for Mental Health and Wellbeing, Mental Health Policy Unit.

NSW: Peter Beumont Eating Disorders Service, Sydney Local Health District, Ramsay Health Care, Northside Group St Vincent’s Hospital Sydney.

NT: headspace Darwin, headspace Alice Springs, Mental Health Alcohol & Other Drugs Branch NT Department of Health, Women, Child & Youth, Top End Health Services (TEHS), Northern Territory Mental Health Coalition.

QLD: Sunshine Coast Health & Hospital Service, Brisbane City Doctors, Queensland Mental Health Commission, QLD: Mental Health Alcohol and Other Drugs Branch (MHAODB), Clinical Excellence Queensland, Queensland Health.

SA: Child & Adolescent Mental Health Service (CAMHS), Women and Children's Hospital, Office of the Chief Psychiatrist.

TAS: Child & Adolescent Mental Health Service (CAMHS), Office of the Chief Psychiatrist, Statewide Mental Health Services, Royal Hobart Hospital, Mental Health Council of Tasmania.

VIC: Child & Youth Mental Health Service (CYMHS) Alfred Health, Austin Health, Adult Community Mental Health Bendigo Health, Centre for Mental Health Learning (CMHL), Monash Health Paediatric Services, Mind Body Well, Nourish. Nurture. Thrive., The Royal Children's Hospital Melbourne, Mental Health and Drugs Branch Victoria Health and Human Services.

WA: East Metropolitan Youth Unit (EMyU), North Metropolitan Health Service, Shenton Park Family Psychiatry, The Hollywood Clinic Ramsay Health Care, Western Australia Mental Health Commission, Department of Health.

Primary Health Networks (PHNs)

Central and Eastern Sydney PHN, Gold Coast PHN, Victorian and Tasmania PHN Alliance, Western Australia PHN Alliance.

Universities:

Deakin University, Flinders University, La Trobe University, The University of Melbourne, Monash University, Swinburne University of Technology, The University of Sydney, The University of Queensland, Western Sydney University.

Mental Health organisations:

Beyond Blue, headspace, Mental Illness Education; Orygen Youth Health.

Government:

Australian Government National Mental Health Commission, Australian Government Department of Health.

Conflict of interest declaration:

InsideOut Institute is Australia's national research and clinical excellence institute and would likely apply for any competitive tender or project grant that is made available in response to the recommendations made in this document.

Contents

Foreword

The Australian Government is deeply committed to enabling our world class researchers to improve the lives of Australians who have either developed or are at risk of developing an eating disorder, along with their families, friends, supports and communities. The very highest quality research and translation of that evidence into practice is essential to improve outcomes for people experiencing this serious group of illnesses.

In recognising the devastating effect of eating disorders on the Australian community, the Australian Government commissioned the first Australian Eating Disorders Research and Translation Strategy. The Strategy provides a framework for bringing together partners across government, health, academia, research, private and nongovernment organisations, and people with a lived experience and their families, friends and supports. I am challenging everyone involved to work collaboratively to ensure the greatest impact on the lives of Australians.

Research plays a vital role in protecting and promoting the health and wellbeing of Australians. It is central to the task of preventing illness and reducing the morbidity and unacceptably high death rate from eating disorders. Quality research increases what we know about these illnesses, successful interventions, and how best to embed the interventions across the many parts of the health system and broader community.

Australia has internationally recognised strengths in eating disorders research. Building on these strengths we can contribute to the international scientific endeavour and make the best use of knowledge generated in Australia and offshore, to address local challenges. The Government, the tertiary education sector, the health sector, the community and private enterprise – in collaboration with people who have a lived experience of eating disorders - all have roles in making this process successful. This Strategy provides that foundation.

The high levels of interest and involvement in the development of this Strategy reflect the importance Australians place on health research and the translation of that research into practice. Preventing eating disorders and improving the lives of people who have an eating disorder is achievable. The guiding principles, strategic priorities and recommended actions set out in this Strategy will help to achieve this vision.

We cannot underestimate the challenge ahead. While we have made significant inroads in addressing eating disorders in Australia, there is much more work needed to ensure new knowledge is accessible to people delivering and using services.

The Hon David Coleman MP
Assistant Minister to the Prime Minister for
Mental Health and Suicide Prevention

September 2021

Statement from the National Mental Health Commission

Australian Eating Disorders Research & Translation Strategy 2021-2031

We know that in 2021 more than 1 million Australians have an eating disorder. Supporting them are families, friends, teachers and colleagues. Their treatment teams include clinicians, health and allied health workers and peer workers, informed by the work of our researchers.

The number of people diagnosed with eating disorders continues to increase, accelerated by the impacts of the COVID-19 pandemic.

Eating disorders are complex neuropsychiatric disorders with high rates of mortality. They impede all aspects of a person's life and cut too many short. The impacts of these illnesses are horrific.

How can we prevent an eating disorder? Why are numbers increasing? What are the causes? What is the most effective treatment for someone and how can they be supported into sustainable recovery?

The answers must be found through the lens of our researchers. An evidence-based approach, drawing on lived and living experience as well as multiple disciplines across genetics, neuroscience, biology and psychology, is essential. The evidence base must then be translated into treatment and support services that meet real need, as early as possible in illness and in episode.

A nationally coordinated and consistent approach to research and its translation is the pathway forward. Australia's researchers are internationally acclaimed and at the frontier of developing innovative new knowledge about eating disorders. Never has it been more important to support this work and the development of a national research framework.

We commend the Australian Eating Disorders Research & Translation Strategy 2021-2031. The collaboration and consultation that has been undertaken is to be applauded, involving 80 organisations, ten peak bodies and key stakeholders.

The engagement of so many, the co-design approach, and the focus on addressing diversity, impact, and necessary research supports has resulted in a strategy that will inform research development in effective prevention, and person-centred treatment and recovery support. It will help drive our collective commitment to reducing the prevalence and impact of these crippling illnesses.

Congratulations to the InsideOut Institute and the work of the Expert Advisory Group under the Co-Chairs Stephen Touyz and John Feneley, in leading this important initiative.

CMorgan

Christine Morgan

CEO / Commissioner – National Mental Health Commission

National Suicide Prevention Adviser

Statement from the Advisory Committee

In 1868, in his address to the British Medical Association at Oxford, Sir William Withey Gull referred to a "particular form of disease occurring mostly in young women, characterised by extreme emaciation" – this was the first description of what came to be known as anorexia nervosa. In the 150 years since, a number of eating disorders have been described – all of which have potentially serious medical and mental health impacts. Despite significant advances in the treatment of eating disorders, particularly over the past 30 years, there remains little understanding about how to prevent them and there is a long way to go to achieve effective, timely, acceptable and accessible approaches for people who experience these complex illnesses.

People who experience eating disorders, and their loved ones, often experience significant stigma, discrimination and prejudice, because their illness and lived experience are poorly understood within the community and in many health care settings. At an individual level, this lack of understanding can impact on help seeking, treatment and outcomes, and at a systemic level, has led to a relative paucity of funding for eating disorder research and translation compared with illness burden. Considering the appalling outcomes in terms of quality of life and the unacceptably high mortality associated with eating disorders, addressing this inequity is urgently required.

The challenge is very significant. There may be no other group of illnesses which, by their very nature, traverse so many dimensions of human experience. Research and therapeutic approaches need to encompass physical and mental health disciplines, academic and lived experience perspectives, differing world views and evolving societal attitudes to and understanding of gender, culture and the impact of trauma.

By bringing together people with lived experience, researchers, clinicians, service providers and eating disorder organisations from around Australia, this project has marked a clear path forward, demonstrating what can be achieved by combining expert perspectives in a co-design process, moderated by good will and shared purpose.

The Australian Eating Disorder Research & Translation Strategy 2021-2031 identifies what action is required now and establishes a respectful process and framework for the future. It will help guide the development of a robust research ecosystem, which will in turn support a dynamic therapeutic space that can readily introduce important new ideas – from a range of innovative sources – to prevent illness, and better treat and support people with eating disorders, their families and loved ones.

We wish to express our gratitude to the Hon Greg Hunt MP, Australian Government Minister for Health and Aged Care, for recognising the great need in this area and embarking on an exacting, inclusive process to strengthen eating disorder research and translation in Australia, now and into the future. We also want to thank the Hon David Coleman MP, Assistant Minister to the Prime Minister for Mental Health and Suicide Prevention for his support of the Strategy and his commitment to urgently transforming research and its translation into tangible clinical improvements.

We acknowledge and thank all participants in our nationwide consultation, who gave so generously of their time and expertise over many months to develop and refine this Strategy. In particular, we wish to thank the members of the Advisory Committee, our colleagues in this journey. Their commitment to a shared process of co-design, their rigorous but respectful engagement, their attention to detail and willingness to keep an open mind made it possible to solve the myriad challenges which inevitably confront a project of this complexity. Most importantly, the Committee never lost sight of those whose lives are impacted by eating disorders.

Finally, we wish to acknowledge and thank the Project Team at the Inside Out Institute and Ms Peta Marks in particular, for their expertise and tireless efforts in supporting and advising the Committee. Without their professionalism, in driving the exhaustive process of co-design and shepherding the editing and production of the final document, delivering the Strategy would not have been possible.

John Feneley

Inaugural NSW Mental Health Commissioner

Co-Chair, National Strategy Advisory Group

Stephen Touyz

Director, InsideOut Institute

Co-Chair, National Strategy Advisory Group

Key stakeholders

We are united in our determination to improve the health and wellbeing of people with eating disorders in Australia. The strategic priorities, recommendations and actions outlined in this document represent our collective thinking around how we can support that objective by improving knowledge generation and the use of knowledge in practice in Australia.

National Eating Disorder Organisations

InsideOut was honoured to lead the development of the first national research & translation strategy for a mental illness group in Australia. This co-designed Strategy has been developed through broad national consultation and collaboration across the sector.

It is our hope that this document provides a blueprint for growth and supports generation of research that changes people's lives.

Butterfly Foundation welcomes this Strategy and the opportunities it will provide for the exchange of knowledge between researchers, practitioners and most importantly those we are here to serve – people with lived experience and their loved ones.

The National Eating Disorders Collaboration recognises that nationally coordinated eating disorder research priorities and direction will deliver the best outcomes for people living with eating disorders and their families.

The Australia & New Zealand Academy for Eating Disorders welcomes this Australian Eating Disorders Research & Translation Strategy and commends the focus on collaboration between researchers, clinicians, treatment providers, and those with a lived experience as an important mechanism for workforce development and improving health outcomes, goals to which our organisation and members are committed.

Eating Disorders Families Australia welcomes the development of the Australian Eating Disorders Research & Translation Strategy, which will prioritise and direct action around the most critical elements of research and translation. This will improve the health system for people with eating disorders and their families and reduce the length and amount of suffering that they all experience as a result of these complex mental illnesses.

State and Territory Eating Disorder Organisations

CEED
THE VICTORIAN
CENTRE OF
EXCELLENCE IN
EATING
DISORDERS

eating disordersqld.

eating
disorders
victoria

Centre for
Clinical
Interventions
• Psychological therapy
• Research • Training • Resources

WA Eating Disorders Outreach &
Consultation Service (WAEDOCS)

Government
of South Australia
SA Health

Metro North
Health

Queensland
Government

Introduction

Release of the Australian Eating Disorders Research & Translation Strategy 2021-2031 is an important milestone for the eating disorder community and for the millions of Australians who experience an eating disorder, their families and supports.

The Strategy has been developed through a two-year national consultation and collaboration process, building on the work of the Australian research community, clinicians, service providers, eating disorder organisations and the vibrant and engaged Australian lived experience community. It is the first disorder-specific strategy that has been developed in consultation with the National Mental Health Commission, informed by their work in developing the forthcoming National Mental Health Research Strategy.

Underpinned by the principles of co-design, impact, research supports, collaboration and diversity, the strategic priorities and recommendations outlined in this document provide the roadmap to establish eating disorders as a national research priority. It will support the ongoing development of a vibrant research culture, an expanded workforce (which includes those undertaking research and those using research in practice) and transform the research, prevention and treatment landscape for people with eating disorders and their families/supports in Australia.

The eating disorder community is united in our desire to accelerate the pace, scale and impact of research innovation, ensuring the promotion of research that works in real world settings and that transforms service delivery at all levels - improving people's health care experiences and outcomes. We are ambitious in our desire to conduct more research at the point of care (whether this be in the community, in schools, primary care, or in treatment settings) and develop mechanisms to ensure that research evidence is used to inform and transform practice in all settings – driving practice change and encouraging distribution and implementation of effective prevention programs and treatments across a range of health and community settings. Everyone has a role to play.

Scope

This document is focused on eating disorder research and the translation of that research into practice. It does not directly address gaps in clinical services and for the most part it is concerned with the major eating disorder diagnostic groups, although the principles will have relevance across the broader spectrum.

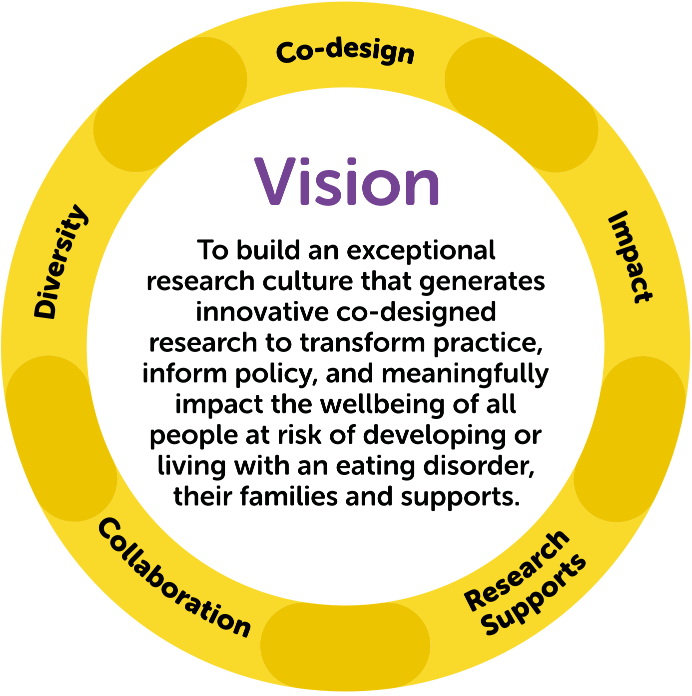
Audience

This document has been developed to inform governments, research bodies, philanthropists, research funders, health services, health service planners and providers, universities and training institutes, researchers, clinicians, and people with a lived experience of an eating disorder, their families, supports and the community.

Strategy snapshot

The five strategic priorities, recommendations and actions outlined in this document have been informed by a range of perspectives provided through a broad-ranging national process led by an Advisory Committee, in collaboration and co-designed with the Australian Eating Disorders Research Collaboration and a Lived Experience Research Advisory Group, and consultation with the National Mental Health Commission.

If formally coordinated, fully funded, and implemented, the Australian Eating Disorder Research & Translation Strategy 2021-2031 will transform the eating disorder research and translation landscape in Australia.



Vision

To build an exceptional research culture that generates innovative co-designed research to transform practice, inform policy, and meaningfully impact the wellbeing of all people at risk of developing or living with an eating disorder, their families and supports.

Strategic Priorities:

1. **A culture of research excellence**
2. **High quality research**
3. **Research workforce capacity and capability**
4. **Accelerate the impacts of research**
5. **Mechanisms for broad implementation**

Guiding principles

Five guiding principles underpin the vision, the strategic priorities, and the actions laid out in this document:

1. **Co-design:** Research is an iterative and dynamic process best informed and co-designed at all stages between researchers, clinicians and people with lived experience, families and supports.
2. **Diversity:** Eating disorder research practice will embrace and embed diversity of culture, gender, body shapes, and sizes, as well as the whole spectrum of eating disorder diagnoses, complexity, severity and recovery.
3. **Impact:** High impact research will address knowledge gaps, build on existing evidence and solve real world problems.
4. **Research supports:** Continuous support and development of research at all levels and stages will ensure the research ecosystem flourishes and delivers outcomes with meaningful impact.
5. **Collaboration:** Supporting and enabling research, research translation and integration of research across systems requires collaboration between individuals, organisations and across sectors. Everyone has a role to play.

Strategic priorities

1	Support and generate a culture of research and translation excellence	A culture that is supportive of research and translation excellence includes strong, effective leadership at all levels. It values the generation of meaningful research that impacts people's lives - so its policies, systems and structures are directed to this objective.
2	Generate high quality research that impacts health outcomes and improves wellbeing	Meaningful, high quality, research requires investment from multiple/varied sources, allocated commensurate with illness burden, morbidity and mortality. Research needs to address urgent knowledge gaps and established priorities that are agreed by the people who are impacted by research.
3	Grow the research workforce capacity and capability	A well-supported research workforce enables research translation and implementation to occur. Growing, supporting and educating the research workforce will foster a talent pipeline of outstanding Australian researchers including academic researchers, clinical researchers and lived experience researchers.
4	Establish a strong translational focus within the research sector and across the system to accelerate the impact of research for people and communities	Innovative, agile, cost-effective co-designed research and evaluation changes the way we do things. Moving research from laboratories into real world settings and accelerating the impact of research requires funding, policies and practice change.
5	Establish quality mechanisms for broad implementation of evidence-based practice and practice informing evidence	Research needs to inform and influence practice, and practice needs to inform research, to have impact on people's health and wellbeing. Establishing mechanisms that increase the use of evidence in practice across the system is central to the challenge of addressing the devastating impact of eating disorders on the health and wellbeing of millions of Australians.

Why research and translation are needed

Eating disorder research, translation and implementation into practice are required to:

- prevent eating disorders
- improve early identification and intervention
- increase access to evidence-based interventions and treatments
- support people with eating disorders and their families
- support and promote research and translation for Aboriginal and Torres Strait Islander peoples
- support and promote research and translation for people from diverse and vulnerable populations
- improve health outcomes
- reduce the unacceptably high mortality rates associated with eating disorders, and
- improve quality of life for all Australians who experience eating disorders, their families and supports.

Research and the translation and implementation of research into practice, affects lives and saves lives.

To date, research innovation in the field of eating disorders has been hampered by insufficient resourcing, reliance on pockets of excellence and a lack of coherent vision and plan, resulting in intermittent discoveries and limited uptake of the evidence. Investment for eating disorder research per affected individual in Australia is significantly less than for autism, schizophrenia or the depressive illnesses [1] [2], despite comparable illness and cost burden [3] [26] [110].

Eating disorders are estimated to affect at least 4-5% of the Australian population at any one time [4] [5] that's 1 million+ Australians, including children, adolescents, adults and older adults, people of all genders, all sexual identities, all cultural groups, all socio-economic groups, in people with all body shapes and sizes, and people with other physical and mental health problems.

Eating disorders are complex mental illnesses that affect people across the age spectrum from early childhood to older age. They have both medical and mental health impacts, and cause often serious social, vocational (education and work), health-related and quality of life impairments. Eating disorders have high mortality rates – Anorexia Nervosa the highest among the mental illnesses – death being a result of both medical complications and mental health deterioration resulting in suicide [6] [7].

Eating disorders commonly affect people at a critical developmental juncture during adolescence and young adulthood. The World Health Organisation notes the impact of poor mental health during this period on people's interpersonal relationships, school performance and work productivity into adulthood. It stresses the importance of developing social and emotional behaviours for resilient mental health and the need to minimise risk factors that will inhibit the potential to thrive into adulthood and participate meaningfully in their community [8].

There is some evidence that eating disorders may be prevented, that early identification and intervention can reduce the duration of illness and improve outcomes, and we know that it is possible for many individuals to make a full recovery if the right treatment is received at the right time [9]. Research efforts that help prevent illness and enhance recovery are vital to achieving the goal of reducing mortality from eating disorders.

People with lived experience repeatedly report that access to care is patchy, inconsistently delivered, difficult to navigate, often not evidence-based and at its worst they report it to be harmful [10-12]. Best available evidence suggests that most will not be identified when they present to the health system [13], 70% of people with an eating disorder will not receive treatment and of those who do only 20% receive an evidence-based treatment [14]. Research that occurs and can be applied in real world settings will improve access to evidence-based interventions.

How research and translation excellence will happen

PARTNERSHIPS & NETWORKS
Collaborate across individuals, disciplines, organisations, sector & community

WORKFORCE
Grow the workforce and develop the research culture

CO-DESIGN
Genuine exchange of knowledge, ideas and experiences

FILL KNOWLEDGE GAPS
Respond to research priorities and the needs of diverse groups

FUNDING
Commensurate with burden and impact

DATA
Capitalise on the potential of big data

We need to conduct research that is co-designed, innovative, rigorous, meaningful and covers all research areas – identifying and responding to diversity. Co-design is a genuine exchange of knowledge, ideas and experiences – an acknowledgement that everyone has expertise that is vital to the process.

Our research should respond to knowledge gaps and identified research priorities, support and value all types of research and be conducted ethically and in line with best practice. It needs to capitalise on existing data sources and consider the potential of big data (large, complex data sets from new data sources).

Funding eating disorder research, translation and implementation commensurate with the burden and impact of eating disorders on the Australian community is essential.

The eating disorder research workforce needs to grow – including academic, clinical and lived experience researchers. This requires a research culture which supports researchers at all stages of their development – from early career through to senior. The eating disorder clinical workforce also needs development - in order that evidence-based treatment is provided and to participate and collaborate in knowledge generation - evidence breakthroughs often come from clinicians.

This requires that services, organisations and research institutions:

- establish structures that support research generation, translation, and implementation,
- engage researchers and research organisations, clinicians and clinical service providers, and
- harnesses the active involvement of people with lived experience, families, and communities.

Eating disorder research and translation hubs, centres, and networks (which include metropolitan, regional, remote and very remote areas) should be developed and build on established strengths that exist across the system. Establishing partnerships and collaborations across and between individuals, disciplines, organisations, sectors and community is key.

Communicating clearly and broadly about the importance of research in the field, the outcome of research and its potential to impact the trajectory of the wellbeing of millions of Australians, will help build engagement and understanding with the community.

What is research translation and implementation?

Research translation is the dynamic and ongoing process of moving research ideas from the laboratory into clinical practice. It ensures that new discoveries become part of the treatments received by people with illness and applies knowledge to improve the health and wellbeing of Australians, strengthen the health care system and support more effective health service delivery [15] [16] [17]. Guidelines are used to 'translate research evidence into recommendations for clinical practice, public health and environmental health' (NHMRC) [18].

Implementation strategies are approaches or techniques used to enhance the adoption, implementation, sustainability and spread of an innovation throughout the health care system [19] [20] [21].

The research process begins with a question. Ideally, research questions are developed through a co-design process [22] between consumers, carers, clinicians and researchers – because it is important that we ask (and fund) exploration of the right questions, in order to create answers that solve real world problems and transform lives.

Health research can be directed towards:

- preventing illness
- identifying risk for illness
- screening, assessing, and identifying illness
- successfully treating an illness (at every stage of its development and for people in all diverse groups)
- care that is individualised and enables engagement and participation in activities that are meaningful, regardless of stage of clinical recovery
- finding a cure – that is, eliminating the illness altogether
- supporting recovery as the person defines it
- ensuring families/carers are supported and able to actively participate in the treatment and recovery of their loved one
- how innovations and treatments work in real life settings and are received by the person and their supports
- workforce development (knowledge, skills, attitudes), and
- models of care and service delivery.

Research translation and implementation is vital. Without these critical elements, research can't lead to improved health outcomes for people and communities.

An important aspect of the research–practice cycle is that it is ongoing. It is always important to question what we do and to collaboratively identify better ways of working and ways to keep improving people's health and wellbeing. Great treatment, prevention, cure and recovery, are rarely the result of a single innovation, but rather the iterative process of researching and improving treatment.

The research-practice cycle

A research question is identified

Co-design across all stages

Research = knowledge production

Translation = knowledge application

Implementation = practice change

BETTER OUTCOMES

Foundations for excellence

Australia has the national structures required of a world leader in the field of eating disorders research, translation, and implementation. We have:

- a peak body for eating disorder professionals - the Australia and New Zealand Academy for Eating Disorders (ANZAED)
- a national charity for people impacted by eating disorders and body image issues, and National Helpline provider - Butterfly Foundation
- a Commonwealth funded national collaboration dedicated to building the system of care - the National Eating Disorders Collaboration (NEDC)
- a national carer support organisation - Eating Disorders Families Australia (EDFA)
- the first open access peer-reviewed journal publishing research in the science and practice of eating disorders - Journal of Eating Disorders (JED)
- a national institute for research and clinical excellence in eating disorders - InsideOut Institute (IOI).

In some areas of research, we are already achieving strongly - Australia has researchers who are recognised world leaders, and high rates of research output, publication and PhD supervision. This is particularly impressive when considered in the context of the low levels of funding and supports for research in eating disorders and mental health more broadly. In other areas of research and translation, there is much work to be done, which is why this Strategy has been developed.

This Strategy supports important documents such as:

- The forthcoming National Mental Health Commission's National Mental Health Research Strategy
- Productivity Commission Mental Health Inquiry Report (2020)
- National Mental Health Commission's Vision 2030 Roadmap: Blueprint for Mental Health and Suicide Prevention (2019)
- ARC Research Integrity Policy (2019)
- The Australian Code for the Responsible Conduct of Research (2018)
- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (2018)
- The National Statement on Ethical Conduct in Human Research (2007) - updated 2018
- Australia's 5th National Mental Health and Suicide Prevention Plan (2017)
- The Australian Institute of Aboriginal and Torres Strait Islander Studies Guidelines for Ethical Research in Australian Indigenous Studies (2012)

1

Overview of Eating Disorders

About Eating Disorders

Eating disorders are common, complex mental illnesses that are characterised by disturbances in thinking and behaviours around food, eating, body, weight and shape [23]. They impact on mortality, disability and health-related quality of life [24] [25], as well as economic and family burden; and they have a range of psychological, social, vocational (education/work) and medical (or physical) wellbeing consequences [26].

Eating disorders have broad impact across the Australian community. They occur across the age spectrum from early childhood [27] to older age [28] [29] [30], in people across all cultural groups, [31] in females and males [32] [33] and other gender identities, in lesbian, gay, bisexual, transgender, queer, intersex, asexual plus (LGBTQIA+) communities [34] [35], in people who experience other mental health problems [36] [37] [38] and substance use disorders [39], in people with other physical health problems [40], and in people of all body shapes and sizes [41] [42] and across the socioeconomic spectrum [43].

Types of eating disorders

Eating disorders can be diagnosed using one of two main diagnostic classification systems: The World Health Organisation's ICD-11 [44] and the American Psychiatric Association Diagnostic and Statistical Manual version 5 (DSM-5) [23], and include:

Anorexia Nervosa (AN) is a complex and potentially life-threatening mental illness that has impairment outcomes comparable to schizophrenia and high rates of psychiatric comorbidity, medical morbidity, and mortality. AN is characterised by persistent restricted food and fluid intake, leading to significantly low body weight and an inability to maintain a minimally normal weight for age and height. The person experiences intense fear of weight gain, disturbance in body image and a denial of illness severity.

Bulimia Nervosa (BN) is characterised by repeated binge eating episodes followed by extreme weight control (compensatory) behaviours such as self-induced vomiting, excessive exercise, food avoidance or laxative misuse. The person's self-evaluation is greatly influenced by body weight or shape. People experiencing BN may be normal weight, slightly underweight or overweight. There is always a sense of lack of control associated with binge eating [45].

Binge Eating Disorder (BED), the most common eating disorder, is characterised by repeated episodes of bingeing, often with a sense of lack of control and marked distress following a binge. Unlike BN, people with BED do not engage in any compensatory behaviours and may be within the healthy weight range or over their most healthy weight. Similar to people with AN and BN, people with BED commonly experience co-occurring mental disorders [46] and significant body image dissatisfaction.

Avoidant Restrictive Food Intake Disorder (ARFID) is characterised by persistent problems with feeding or eating, which result in a failure to meet appropriate nutritional and/or energy needs. Unlike people with AN and BN, those with ARFID do not experience body weight/shape disturbances. Whilst most common in children and young people, particularly those with pervasive developmental disorders such as autism, ARFID may also occur in adults.

Other Specified Feeding and Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED) are eating disorders that cause clinically significant distress or impairment in important areas of functioning, but which do not meet the diagnostic criteria thresholds for AN, BN, BED or ARFID. Despite this, the clinical impact of OSFED and UFED may be as severe as AN and BN and the treatment is usually the same as for the eating disorder where diagnostic criteria are fully met [47].

There are two additional disorders of eating that are included in the 'Feeding and Eating Disorders' category of the DSM-5: **Pica** is characterised by the persistent eating of non-food substances that that have no nutritional value - e.g., ash, hair, dirt or paint. **Rumination Disorder** is characterised by the repeated regurgitation of partially digested food which may then be re-chewed, re-swallowed, or spit out. The principles, strategic priorities, recommendations, and actions in this document will have relevance across the broader spectrum of eating disorders.

Cause, Risk and Protective Factors

Eating disorder researchers have identified multiple and complex causes of eating disorders and a range of risk and protective factors including individual (physiological and psychological), environmental and socio-cultural factors. For example, research has explored:

Age

Risk for eating disorder behaviours increase through adolescence into early adulthood [48] [49] [50]

Biological factors

Genetic, gut microbiota and neurobiological factors [54] [55]

Gender

Females are significantly more likely to develop an eating disorder than males; and eating disorders are significantly under reported in males [56]

Individual traits

Negative affect, low self-esteem, detachment-related personality traits (e.g. inhibition, social isolation) and perfectionism [57] may pre-dispose, exacerbate or maintain dysfunctional eating behaviours [58]

Diverse Populations

Research into eating disorders in Aboriginal & Torres Strat Islander peoples is extremely limited. However, early data suggests that prevalence rates may be higher for some eating disorders than the rest of the Australia community [51]

People in sexual minority groups demonstrate higher rates of disordered eating and emerging data indicates people in sexual minority groups who are transgender or from an ethnic minority may be at elevated risk for disordered eating [52]

The prevalence of eating disorders is higher among elite athletes than the general population, higher in female athletes than male athletes and more common among those involved in aesthetic sports relying on a lean physique, such as gymnastics, boxing and wrestling [53]

Weight and shape concern and body image dissatisfaction is one of the most studied and potent predictors for the onset of an eating disorder [59]. Body image is one of the top three concerns for young people [60]. Weight and shape dissatisfaction, concern about eating, weight and overweight, and the desire to be thinner is consistent across young, middle aged and older women, regardless of their weight [61] [62]. Males are also increasingly reporting body dissatisfaction – their focus being on bulking up and developing muscularity, rather than seeking to be thinner [63]. Internalisation of the thin ideal, weight-based self-worth, food restriction and body dissatisfaction has been reported in lesbian women, gay men, transgender and other gender and sexually diverse people [64] [65]. Transgender youth are reported to experience increased internalisation of the thin ideal, body surveillance, disordered eating and body shame [66].

Eating behaviours

Disordered eating behaviours such as extreme dietary restriction, place people at higher risk of developing an eating disorder [67] and can make it 18 times more likely for young females to develop an eating disorder within 6 months, and an estimated 20% prevalence rate within 12 months [68].

Prevalence

Eating disorders are common (very common in adolescents [69]) and it is clear that they have a significant effect on the health and quality of life of a wide range of individuals across all demographic categories. Concerningly, rates of early detection and intervention are low [13].

There is a lack of accurate data on eating disorder epidemiology and burden of disease in Australia [70] and internationally, and it is therefore difficult to identify a definitive position on the incidence and prevalence of different eating disorders in the Australian and global population. This is an area of research that requires attention for clinical and service planning purposes.

A range of issues are responsible for the lack of current data including:

- lack of financial investment in epidemiological research [71] [72]
- illness-related factors (such as denial, shame and secrecy) and the impact of stigma, discrimination and stereotyping [73] [74]
- the widespread belief that eating disorders are rare illnesses [70]
- different diagnostic thresholds (changes to criteria has had an impact on AN and EDNOS/OSFED and UFED diagnoses) [75]
- exclusion of eating disorders from national mental health surveys [70], and
- small numbers of large-scale population-based research projects [76].

Using studies that do exist, it can be estimated that well over one million Australians (at least 4-5% of the population) [76] [77] are affected and the experience of eating disorder symptoms is increasing across a range of diagnoses [77-79]. BED is consistently reported as having the highest prevalence rates among global populations, but few global prevalence studies have measured the prevalence of new DSM-5 disorders OSFED, UFED and ARFID. Research suggests BED and OSFED are the most prevalent disorders in Australia [57] [77].

People with ARFID tend to be younger than those with AN or BN, a higher proportion are males, and comorbid psychiatric and or medical symptoms are common [80]. ARFID is a recently defined disorder, therefore research regarding prevalence, risk, effective treatment, illness course and outcomes is particularly limited [81]. Although AN tends to be the least common eating disorder in community samples, the severity of the disorder results in a higher representation in clinical populations. However, only a small proportion of people with eating disorders, including those with anorexia nervosa, receive targeted eating disorder treatment [82].

Eating disorders are associated with high levels of morbidity and mortality [7] – in fact, research suggests AN has the highest mortality risk ratio of all (non-substance use related) mental disorders [6, 83, 84]. Eating disorders are also associated with very poor mental health related quality of life [77].

Although they occur at any age, eating disorder prevalence is highest among adolescents and young people [69].

For Australians aged 15+ prevalence of an eating disorder is estimated at between 4-16% [48] [5] [85] [86] [57] [87] [88] [89] with estimates varying depending on the diagnostic category [90] and a range of other variables (e.g., gender).

People with eating disorders experience higher rates of co-occurring mental health problems than people in the general population – particularly depression and anxiety disorders, and including substance use disorders and personality disorders [40]. Psychiatric comorbidity in eating disorders exists across the lifespan [6, 80, 91, 92] and impacts on prognosis, social and psychosocial impairment, mortality [55] and course of illness [93-95]. Significant physical comorbidities [40, 96-98] can also occur.

Social and economic impact

Most Australian eating disorder research does not include an evaluation of social and economic cost. Research that has been conducted has identified that people with eating disorders (particularly AN and BN) experience significant social and economic impairment. This is an element of the research that should be enhanced in future to ensure evidence is available.

> **'Eating disorders are disabling, deadly, and costly mental disorders that considerably impair physical health and disrupt psychosocial functioning' (p899) [99].**

Improving a person's mental health benefits their social and economic participation, engagement, and connectedness, as well as their productivity (educational attainment, employment) over their lifetime. It also provides flow-on benefits to families and friends (e.g., in terms of lower carer burden), and to the community where there is a more productive workforce and increased community output, more volunteering and community contribution, and greater national income and living standards – which in turn raises the nation's capacity to invest in interventions that improve mental health [100-104].

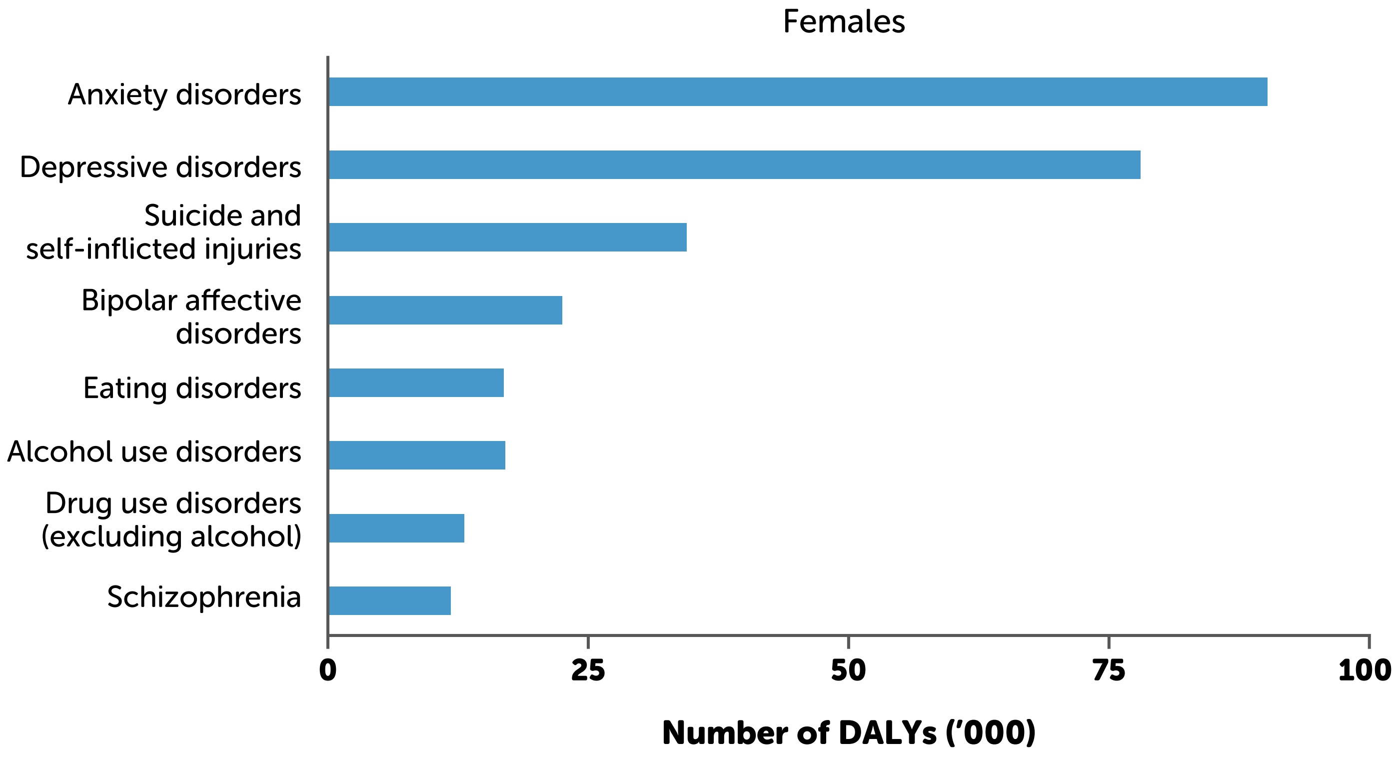
Burden on individuals

The personal burden of living with an eating disorder is significant. People describe experiences of misery – loneliness, despair, hopelessness, and intense mood swings. The person never feels 'good enough', is never able to 'achieve success', is unable to engage in pleasurable activities and suffering is a given. Emotional and social delays can be related to years where the person is restricted to a limited range of interests and has few free choices, lack of opportunity or ability to form friendships and a focus on more solitary or family-based activities. Quality of life is impacted and people with enduring illness may struggle to meet their personal life goals including having a partner or family [105].

Burden of disease

Eating disorders lead to the loss of healthy years of life. In 2017, it was estimated that over 3.3 million healthy life years were lost to eating disorder-related disability worldwide. This equated to 9.4 years lost to disability (YLD) for AN and 33.8 YLD for BN, per 100,000 population. Eating disorders represented 2.8% of the mental disorders rate of years lived with disability. The overall rates for mental disorders decreased slightly over the period 2007 to 2017. However, over this same period, the YLD rates for anorexia increased by 6% and for bulimia by 10% [26]. Health loss varies by gender, across area of residence and by socioeconomic groups. Graph 1 (below) demonstrates the types of mental illness that contribute to health loss of females, who experience greater loss due to anxiety disorders, depressive disorders and eating disorders than males do.

Graph 1: The health loss of females associated with mental illness [106] expressed as Disability Adjusted Life Years (DALYs)



Source: Productivity Commission 2020

Globally, AN and BN together (not including other eating disorders) are the 12th leading cause of disability in 15-19 year-old females from developed countries [71].

The gap between current health and the ideal situation, where everyone lives into their old age free of disease and disability, is known as the 'burden of disease'. Table 1 (below) shows the 2017 global years lived with disability for all causes, non-communicable diseases, mental disorders, and estimates for eating disorders and anorexia and bulimia nervosa. From 2007 to 2017, years lost to disability 'remained constant or decreased slightly for all causes, non-communicable diseases, and mental disorders overall' (p523), but increased for anorexia nervosa (by 6%) and bulimia nervosa (by 10%) [26]. However, lack of or limited data means estimates of eating disorder prevalence and burden must be interpreted with caution [107].

Years lived with disability (YLD)			
	COUNTS (thousands)[c]	Age-standardised rate per 100 000 population[d]	Change 2007-2017 (%)[a]
All causes	853 043	10 870.5	- 0.9
Non-communicable diseases[a]	678 294	8579.1	0.1
Mental disorders[b]	22746	1560.1	-1.1
Eating disorders	3352	43.1	9.4
AN	716	9.4	6.2
BN	2636	33.8	10.3

[a] Including mental disorders
[b] Substance use disorders not included: these form a separate category
[c] Data from Global Burden of Disease (GBD) Study 2017, Lancet 2018; 392:1789–1858.
[d] Data from GBD Study 2017, Institute for Health Metrics and Evaluation (IHME), 2018.
Source: van Hoeken and Hoek 2020

In Australia, the Australian Institute of Health & Welfare (AIHW) identify eating disorders as among the leading causes of disease burden in children (5-14 years) and the 10th leading cause of non-fatal disease burden for females aged 15-44 years - causing greater burden than alcohol use disorders, gynecological disorders or interpersonal violence [108].

Impact on families and carers

Eating disorders have been found to have powerful consequences for families and carers – with high rates of psychological distress, hardship and a high out-of-pocket cost burden [109].

Research has found that both objective and subjective burden is high for parents/carers of people with eating disorders - higher than for carers of people experiencing depression or schizophrenia [110] [111]. Caring for and living with someone who has an eating disorder has been found to adversely impact health and mental health, quality of life and employment, increasing distress and anxiety, depression, social isolation, burden and expressed emotion [112] [113].

> “There is no school to attend to prepare anyone to care for someone with an eating disorder. No diploma to be earned or degree. Suddenly you are thrown into a situation that feels like you’re swimming upstream – with no land in sight.
>
> We feel the heavy burden of helplessness and hopelessness in the face of a harrowing and unrelenting illness. The eating disorder is the elephant in the room with its constant desire to split families, disarm siblings and turn the table on carers. It’s a long hard road full of emotional, financial and physical challenges – but we don’t give up.
>
> Working towards recovery and ‘life’, for both the one enduring the pain of the eating disorder and the family, is worth the fight.”
>
> Bronwyn Carroll, Carer

The input required from families as part of the treatment team is significant and requires skillful caregiving, particularly in the early phases of illness and especially (though not exclusively) for children, adolescents, and young people [114]. This objective burden, in the form of direct care to support eating is required, and it can be a protracted process. Subjective burden is also high, that is, the psychological distress experienced by carers associated with stigma, role strain (feeling like their caregiving isn’t effective) and through not having their own support needs met (e.g., being provided with insufficient information) [115]. Family relationships, interpersonal dynamics and the coping resources of families can be challenged [116]. Most of the limited research about carer wellbeing identifies significant unmet need [117]. However, psychoeducation programs have shown to be effective in helping to reduce the distress and burden carers experience [265] [266].

The impact of a family member with an eating disorder is not just on parents or carers. ‘Having a sibling with an eating disorder can impact on healthy siblings in many ways including negatively affecting their quality of life, their sibling bond, and their physical, mental and emotional health’ (p40) [118].

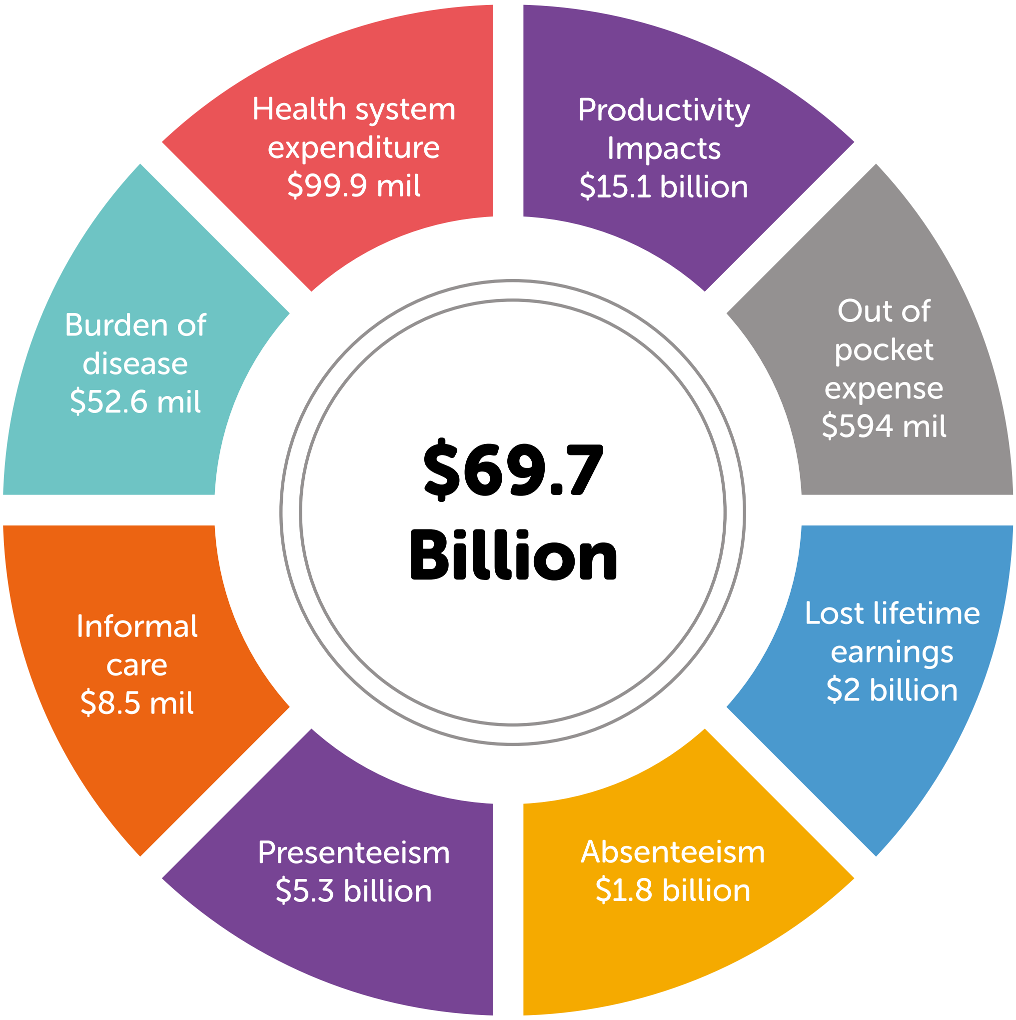
The cost burden of caring for a person with an eating disorder is also substantial. Australian research has found that households experience significant financial burden associated with eating disorder treatment [109] - perhaps not surprising given that the majority of specialist services in Australia are provided by the private health care system and by private psychology providers where significant payment gaps often exist [82, 101, 104, 119]. In addition to the direct costs are the lost-income costs, where families/carers need to forego opportunities to earn in order to access or attend appointments or undertake other caring duties.

Health service utilisation & economic cost

People with eating disorders utilise health services more than people with any other type of mental illness [120] [121]. Eating disorders are the 12th leading cause of mental health hospitalisation costs within Australia [122]. In the 2019 Productivity Commission inquiry into Mental Health, Private Healthcare Australia noted that people with schizophrenia and other acute psychiatric disorders are predominantly treated in public hospitals, while people with anxiety and eating disorders are primarily treated in private hospitals [123]. The expense of treatment of an episode of AN has been reported to come second only to the cost of cardiac artery bypass surgery in the private hospital sector in Australia [124].

The only economic and social impact analysis in Australia was conducted in 2012 by the Butterfly Foundation with Deloitte Access Economics [125] and conservatively estimated that the total socioeconomic cost of eating disorders at that time was $69.7 billion dollars. As diagram 1 (below) identifies, in those estimates, both direct costs to the health system and to the individual were significant as were the indirect costs associated with eating disorders.

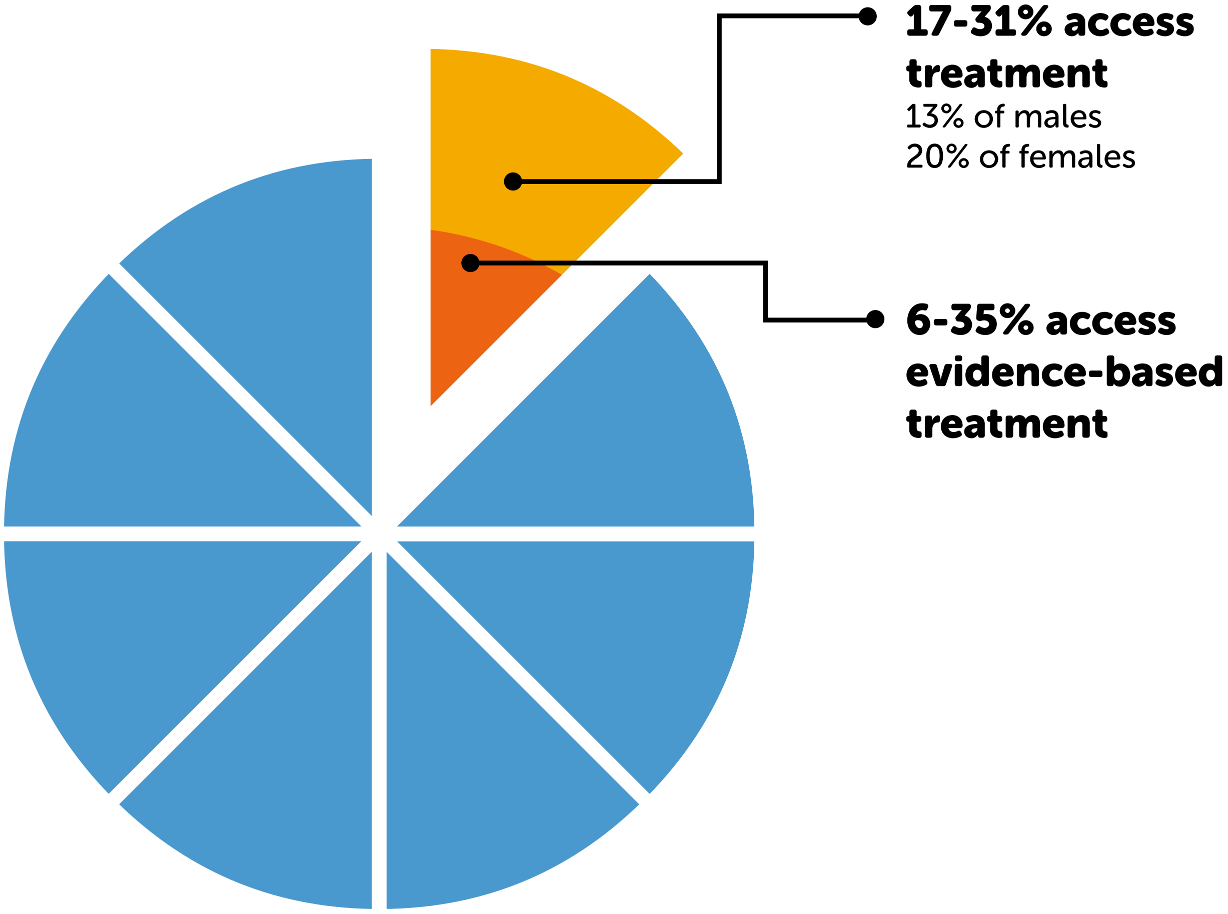
Diagram 1: The social and economic cost of eating disorders (as per Deloitte Access Economics 2012)



Australian researchers found that in South Australia in 2018, the average cost of years lost to disability for people with BN and BED was $269,649 per person – that's 'two-thirds of the costs borne by individuals and the wider community'(p1). The authors note that these costs should be considered when assessing the potential benefits of prevention and management initiatives [126].

Of great concern, is the finding that in Australia, very few people with eating disorders are picked up in primary care [13] and as few as 17-31% of people with eating disorders seek eating disorder treatment - only 13.6% of males and 20% of females with an eating disorder (see diagram 2 below) [14]. For those who do access care, it is unlikely to be evidence-based, with estimates ranging from just 6-35% of specialist clinicians reporting using evidence-based protocols, many stating they use an eclectic mix and many omitting key elements of evidence-based approaches [127]. 'If it is the case that few are seeking treatment, then many individuals with eating disorders are suffering needlessly'(p728)[14].

Diagram 2: Estimate of people with eating disorders who access treatment, and treatment that is evidence-based



The context in which research and translation occurs

It is impossible to discuss strategic planning for research and translation for any illness group without considering the relevant community and health services that are available – as this is the context in which research occurs and is the end-point of all translational work. Many individuals, organisations and key stakeholders who contributed to the development of this Strategy cited lack of adequate clinical capacity as the single biggest barrier to the translation and implementation of research findings.

Conducting authoritative research into the cause(s) of an illness requires that people at risk of or experiencing the illness can be identified – either in the community, or in clinical, or other settings. Early identification and intervention research requires that health practitioners have the knowledge, skills and confidence to identify those at risk or with symptoms; and because research into treatments, recovery and clinical outcomes is intrinsically linked to clinical care delivery, clinical service development and the growth of a culture of research excellence, these will happen best alongside each other. Translation cannot occur without a service or setting in which to translate the research finding, and good translational research is intimately connected to the service setting, the intervention recipients, and those delivering the service or intervention.

Even great research will have no impact without access to clinical populations (that is, people who experience or are at risk of developing a particular illness) and a community or clinical service in which to test and then deliver the innovation. Researchers need access to people with eating disorders and their families, and the community and treatment settings to translate research into practice change.

Current eating disorders policy, services and support in Australia

Access to specialist eating disorders treatment in Australia is variable depending on where a person lives. These differences reflect differing policy contexts and approaches in each state and territory, service funding (for specialist services, positions, and workforce/service development), and the availability of consumer and carer support organisations.

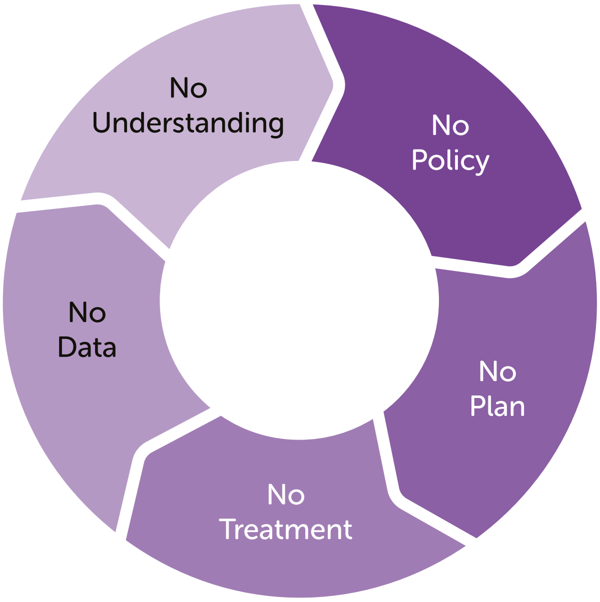
A current policy and funding initiative by the Australian government is focused on providing early-stage interventions and treatment interventions in primary care. Since late 2019, people with eating disorders have been able to access up to 40 evidence-based Medicare Benefits Scheme (MBS) funded psychological treatment sessions and up to 20 dietetic sessions per year. The Australian government has also funded the construction of an Eating Disorder Residential Service in each State and Territory. The first one recently opened in Queensland.

As treatment options increase, there is an urgent need to ensure that research informs the development of the workforce and service systems, enabling them to deliver the most up-to-date evidence-based care; to transform the health system and equip it with systems to deliver scalable and effective models of care, and tools to assess and monitor performance.

Policy

The National Agenda for Eating Disorders 2017-2022 [128] identifies the role of policy in ensuring early access to the right type of treatment that enables sustainable recovery in-line with the fifth National Mental Health Plan [129] (see diagram 3 below). The purpose of the Agenda is to provide guidance for the establishment of a baseline of accessible evidence-based treatment for people with eating disorders and their families, defined as: 'early, affordable access to a variety of safe, evidence-based treatment and recovery support that is specific to eating disorders and inclusive of support for the critical role of families and carers' (p4).

Diagram 3: The role of policy



Ref: Adapted Butterfly Foundation National Agenda for Eating Disorders 2017-2022, p6

Policies relating to, or targeting, eating disorders differ by jurisdiction as outlined in Table 2 (below). As at 2021, NSW Health is the only jurisdiction to publish an eating disorder specific Service Plan. There is no national eating disorder specific service plan, strategy or framework.

Table 2: Jurisdictions eating disorders policies and guidelines

Jurisdiction	Policy or Guideline
ACT	ACT Eating Disorder Position Statement Under development: Territory-wide Model of Care for Eating Disorders
NSW	NSW Service Plan for People with Eating Disorders 2021-2025 NSW Service Plan for People with Eating Disorders 2021-2025 – Blueprint for Action
NT	No current policy or guidelines
QLD	Connecting Care to Recovery 2016-2021: A plan for Queensland's State-funded mental health, alcohol and other drug services
SA	The SA Health SEDS Model of Care for Eating Disorders in SA uses a collaborative approach to care with other SA Health mental health teams.
TAS	Tasmanian Eating Disorder Service Statewide Operational Service Model 2021
VIC	Eating Disorders Strategy
WA	In WA, the Mental Health Commission with North Metropolitan Health Service (NMHS) have developed a proposed eating disorder state-wide model of care (MOC).

Eating disorder services in Australia

Access to eating disorder specific community-based services and inpatient beds are limited.

Designated funded eating disorder beds

People with eating disorders are admitted to hospital for medical and mental health treatment in all states and territories. However, treatment is usually provided as part of a medical or mental health/general service, and is not funded as a designated eating disorder service/bed. Designated, funded eating disorder beds are identified in diagram 4 (below). There are also a number of hospitals across the country where public health services provide specialist treatment for people with eating disorders, however, the beds are not designated funded eating disorder beds.

Diagram 4: Designated funded eating disorder beds in Australia

Queensland
5 public beds
20 private beds

New South Wales
15 public beds
55 private beds

Victoria
15 public beds
35 private beds

Western Australia
private beds
(unspecified number)

Designated publicly funded eating disorder services

People with eating disorders can and do access treatment (and trained clinicians) across publicly funded general and mental health services nationally - such as in headspace, primary care, child and adolescent mental health services (CAMHS), adult mental health services, general medical (pediatric and adult) and mental health inpatient units and outpatient clinics. However, access to eating disorder specific, publicly funded services – inpatient, outpatient, day program/intensive - are only available in some states and territories and are predominantly available in metropolitan areas (Table 3 below).

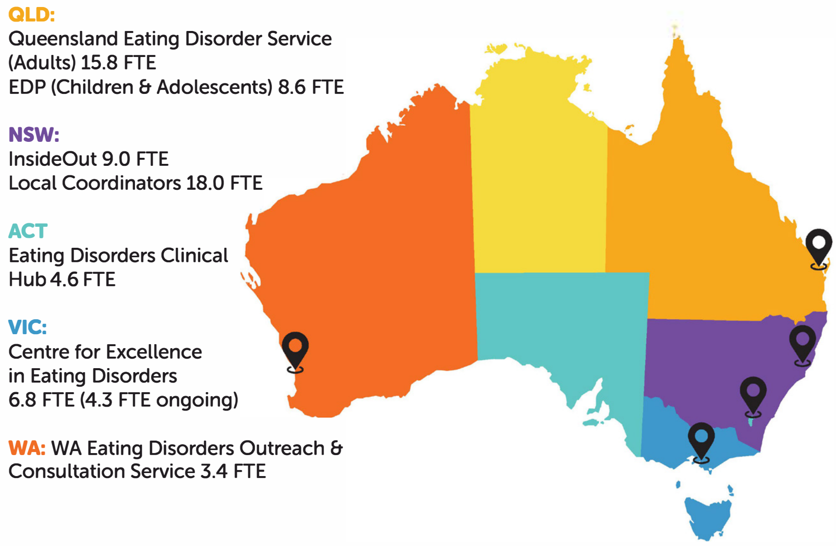
Table 3: Eating disorders specific public funded services by Jurisdiction

Jurisdiction	Inpatient	Outpatient	Day Program/ Intensive	Location of services
ACT		✓		Canberra
NSW	✓	✓	✓	Sydney, Newcastle, Wollongong
NT		✓		Darwin
QLD	✓	✓	✓	Brisbane with consultation support services in Gold Coast, Sunshine Coast and Cairns
SA		✓	✓	Adelaide
TAS			✓	Statewide service under development
VIC	✓	✓	✓	Melbourne, Barwon, Bendigo
WA		✓		Perth

Service development and workforce training

Service development and workforce training are key elements of the provision of a comprehensive service to people with eating disorders. Diagram 5 (below) shows the staffing levels (expressed as Full Time Equivalent FTE) of funded eating disorder service development and workforce training services, and organisations available in Australia.

Diagram 5: Funded eating disorder service development and workforce training in Australia



Consumer and carer support

Eating disorder NGO's and community support organisations have a vital role in:

- enabling support for people experiencing an eating disorder and their families
- helping people to navigate the health care system and access services
- representing the voice of people with a lived experience of eating disorders
- providing peer mentoring services.

Nationally The Butterfly Foundation (Butterfly) is a national charity which provides evidence-based support services, treatments, prevention programs and online resources that respond to the needs of the community. Butterfly's National Helpline provides counselling, referral and advice over the phone, via email and webchat, reaching close to 30,000 people each year. Butterfly also administers the National Eating Disorders Collaboration (NEDC) for the Commonwealth Government Department of Health.

Nationally Eating Disorders Families Australia (EDFA) is a national carer support organisation founded by Australian parents who have cared for and treated a person with an eating disorder. EDFA provides support, information, validation and education, based on lived experience expertise, to empower parents, partners, siblings and other carers on the journey with their own loved one. EDFA provides nationwide support through its **strive** online carer support and private Facebook groups, education seminars, sibling support group, peer-to-peer support, member resources and events.

In QLD Eating Disorders Queensland (EDQ) occupies a unique place within the broader eating disorder service system. The eating disorder treatment environment is predominantly based on a medical approach to working with clients with eating disorders. While EDQ sits outside a purely medical model, we have developed an integrated model of care that fits seamlessly in a Stepped Care model of treatment. Since 1996 EDQ has developed a unique, evidence informed model of care. EDQ is funded by Queensland Health through the Connecting Care to Recovery Plan (2016), to deliver Community Mental Health Treatment Services for eating disorders including:

- Group support and rehabilitation
- Individual peer work
- Group based peer work
- Individual carer support
- Group carer support
- Structured psychological therapies.

In VIC Eating Disorders Victoria (EDV) is the leading community organisation helping Victorians understand and recover from eating disorders. A trusted source of support since 1983, EDV delivers a broad range of free and low-cost community services that respond across the breadth of the eating disorder experience – from discovery to recovery. EDV exists to:

- Guide Victorians to the services needed for timely, evidence-based care.
- Share with Victorians the skills developed by those who have experienced and recovered from eating disorders.

- Provide Victorians with innovative community programs that aren't available elsewhere.
- Be a voice that guides Victorian stakeholders (health professionals, community leaders, decision makers) to the knowledge required to strengthen the broader system of care.

EDV services are for individuals affected by eating disorders, as well as the families, communities and professionals that support them. EDV's work is proudly informed by lived experience, as well as the expertise of health professionals and evidence-based approaches. EDV represent a strong voice for lived experience and actively advocate for the community affected by eating disorders at local and national level.

In WA the Women's Health and Family Service runs the Body Esteem Self-Help Group 20-week program, individual peer support and a one-day workshop to help parents/partners gain a deeper understanding of what their loved one might be experiencing as part of their Parent/Partner Support Program (PESP).

In other states and territories, people with a lived experience provide input into service development and program initiatives through lived experience representation on committees and working parties.

2

Eating Disorders Research

The existing knowledge base

The history of research into eating disorders

Forms of eating disorders and eating disorder symptoms (such as self-starvation, binge eating and self-induced vomiting) have been described in historical, medical and religious texts since ancient times (the first recorded death by self-starvation was in a religious text around 383AD [130], and have varied in frequency, manifestations and possible motivation [131].

Richard Morton, a British physician is credited with the first medical description of AN in 1689, followed by two separate descriptions in 1873 by French physician Charles Lasegue and British physician, Sir William Gull [130]. In 1903 Dr Pierre Janet published the first observations of bulimic behaviours [132], and in 1959 Dr Albert Stunkard first described BED [133].

AN was the first eating disorder to be included in the Diagnostic and Statistical Manual (DSM-1) in 1950. The DSM-111 (1980) listed AN and described bulimia symptoms, included under the category of disorders of childhood or adolescence. BN was then listed as a separate eating disorder for the first time in DSM-III-R (1987). In DSM-IV (1994) BED was included as a disorder for further research. In the revised edition of DSM-IV-TR (2000) eating disorders were given their own category (Feeding and Eating Disorders of infancy or early childhood) [134] and in DSM-5 (2013) the revised title 'Feeding and Eating Disorders' included the addition of three disorders (avoidant/restrictive food intake disorder, rumination disorder, and pica) and the inclusion of BED as a formal diagnosis [135]. Research into treatments for people with eating disorders began in the early 20th century, focusing initially on descriptive clinical accounts and theoretical conceptualisations, with development and testing of therapies published increasingly from the 1970s onward.

The timeline below identifies modern shifts in thinking around causes of eating disorders, prevention, and treatment approaches because of scientific discovery.

Timeline of discovery

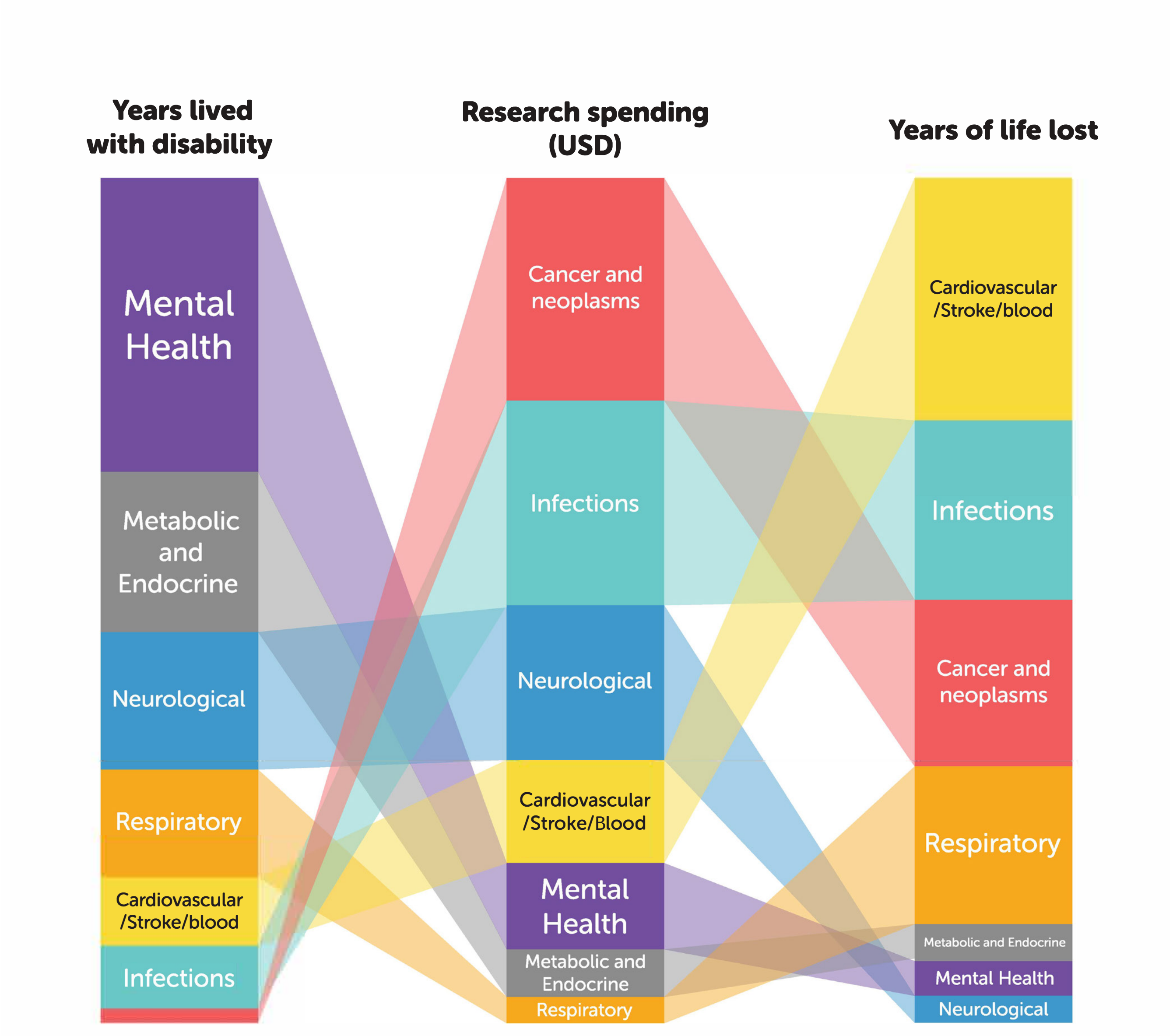
1914	AN was conceptualised as an endocrine illness and the disorder was treated with endocrinological medications. This approach was refuted by WW2 [136].
1940s-50s	Psychoanalysis influenced thinking around AN, which was considered a defense mechanism. Individual psychoanalytic therapy was the therapy of choice.
1960s	Important shifts in thinking about the role of families began - to be less blaming and pejorative but still focusing on changing family functioning [137].
1973	Eating Disorders: Obesity, Anorexia and the Person Within [138] described the relentless pursuit of thinness and the characteristic disturbance of body image found in AN. The psychodynamic approach led to Individual Psychodynamic Psychotherapy for the treatment of AN. The family systems model of psychotherapy emerged, identifying AN as a consequence of family psychopathology.
	Feminist and cultural scholars framed binge-purge behaviours among normal-weight women as 'bulimarexia', seeing BN as a culture-bound syndrome resulting from the obsession with thinness in modern Western culture [139].
1978	The Golden Cage: the Enigma of Anorexia, written in plain language, quoted the experiences of people with the illness and emphasised the importance of early diagnosis [140].
1979	Bulimia Nervosa: An Ominous Variant of Anorexia noted the differences in symptoms and health risks between AN and BN [141].

Late 1970s	CBT for eating disorders was developed in the late 1970s [142]. Dietary restriction and shape and weight concerns were identified as central to the maintenance of BN; a 20 session treatment protocol was established and clinical trials began.
1970s & 1980s	Clinicians at the Maudsley Hospital in London, England, conceived a different form of family based therapy model, treating parents as a resource, not a source of harm.
1984	Australian research comparing lenient and strict AN operant conditioning programs led to more lenient treatment internationally [143].
1990	The first Global Burden of Disease study was conducted and did not include eating disorders.
1990s	CBT was applied to BED [144].
1993	The first reports of eating disorder prevention programs were published.
2000s	Interpersonal Psychotherapy, Cognitive Analytic Therapy, Focal Psychoanalytic Therapy and other psychodynamic therapies were used; exploration of Neurobiology - brain activity, neurotransmission and impact of eating disorders on the brain commenced.
2001	The family-based therapy model was further developed and manualised – known as the Maudsley model of Family Based Therapy [145].
2005	Specialist Supportive Clinical Management (SSCM) was shown in one trial to be more effective than CBT or Interpersonal Therapy [146].
	First descriptions of 'orthorexia' and muscle dysmorphia enter into the literature [147] [148].
2007	Motivation-based therapies – Motivational Interviewing, Motivational Enhancement Therapy – were adapted to treat people with eating disorders [149].
	Research discovered people with BN are particularly responsive to CBT as a first line of treatment and that treatment efficacy – at least initially – may sometimes be enhanced by the adjunct of medication. [150]
2008	An updated treatment manual for Enhanced Cognitive Behavioral Therapy (CBT-E) taking a transdiagnostic approach was published [151].
2010	Global Burden of Disease (GBD) 2010 included AN and BN – the first time burden for any eating disorder had been identified at a global level [107].
2012	The Maudsley Model of AN Treatment for Adults (MANTRA), addresses the obsessional and anxious/avoidant traits that are proposed as being central to the maintenance of the illness [152].
2013	First global recognition of eating disorders; Global Burden of Disease 2013, retrospectively calculated AN and BN burden for 1990, 1995, 2000, 2005 and 2010.
	FBT for AN Manual was updated – to emphasise family processes, communication and the negotiation of adolescent development issues [153].
	ARFID was first described when the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5) was published.
2018	The first medication ever approved for use specifically to treat an eating disorder (Binge Eating Disorder) was approved by Therapeutic Goods Australia (TGA).
2019	DNA from 16,992 people with AN from around the world identified eight genes with direct links to AN, re-conceptualising the illness as a metabo-psychiatric disorder [154].

Mental health research and research funding

A 2020 analysis of global mental health research funding identified mental health research in general is underfunded compared with other (physical) disease areas, particularly in relation to disease burden (figure 1). For example, cancer research and infectious disease research received more than twice as much global investment in research than for all metal health conditions combined. Overall, less than 50c USD/66c AUD per person per year is invested in mental health research globally (about $3.7 billion USD/ $4.945 billion AUD) and the majority (over 96%) is from government/public funding sources.

Figure 1: Burden of disease for selected health research categories compared to amount spent on research (global)



Source: Woelbert et al (2020) p18

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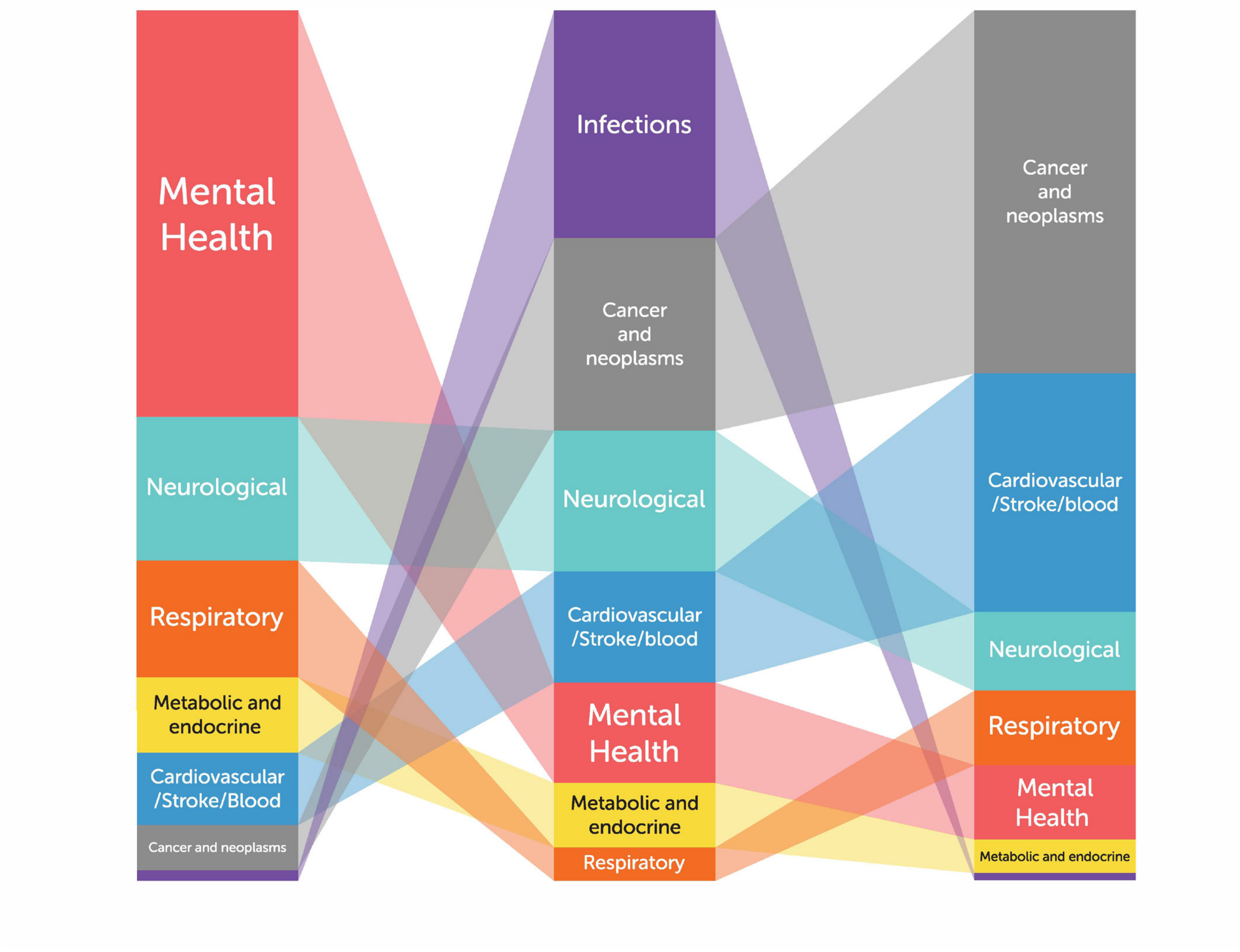
Mental health research funding in Australia is similarly underfunded, however, Australia and New Zealand were the only regions with a significant increase in mental health research funding between 2015 and 2019. Figure 2 highlights the comparison of research funding in Australia and New Zealand compared with disease burden [155].

Figure 2: Research funding in Australia & New Zealand for selected fields compared to disease burden



Source: Woelbert et al (2020) p20
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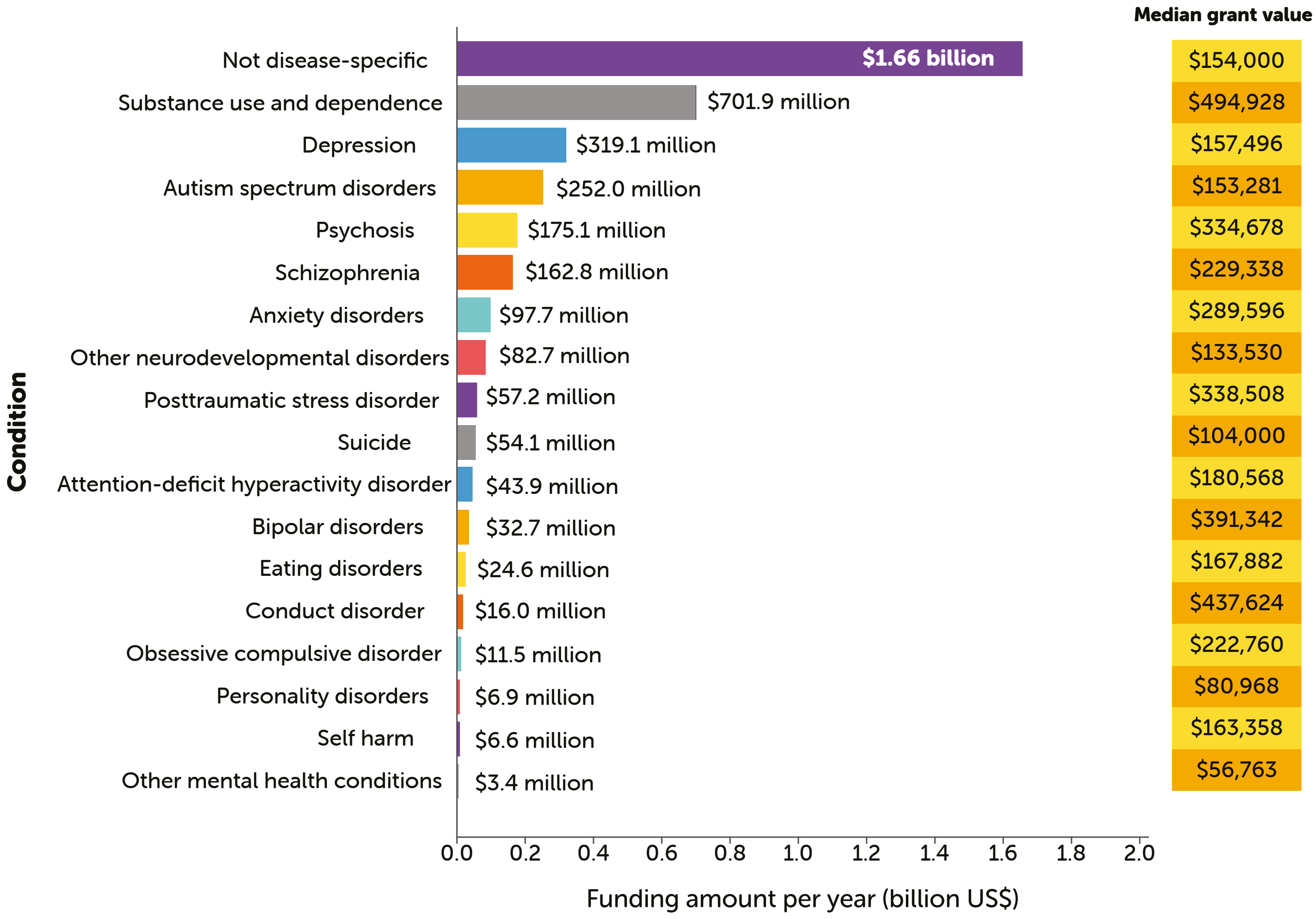
Some fields of mental health research are more relatively underfunded compared to others (specifically, self-harm and suicide, eating disorders, conduct disorder, obsessive-compulsive disorder and personality disorders (graph 2).

Graph 2: Global investments in mental health research by condition



Source: Woelbert et al (2020) p21

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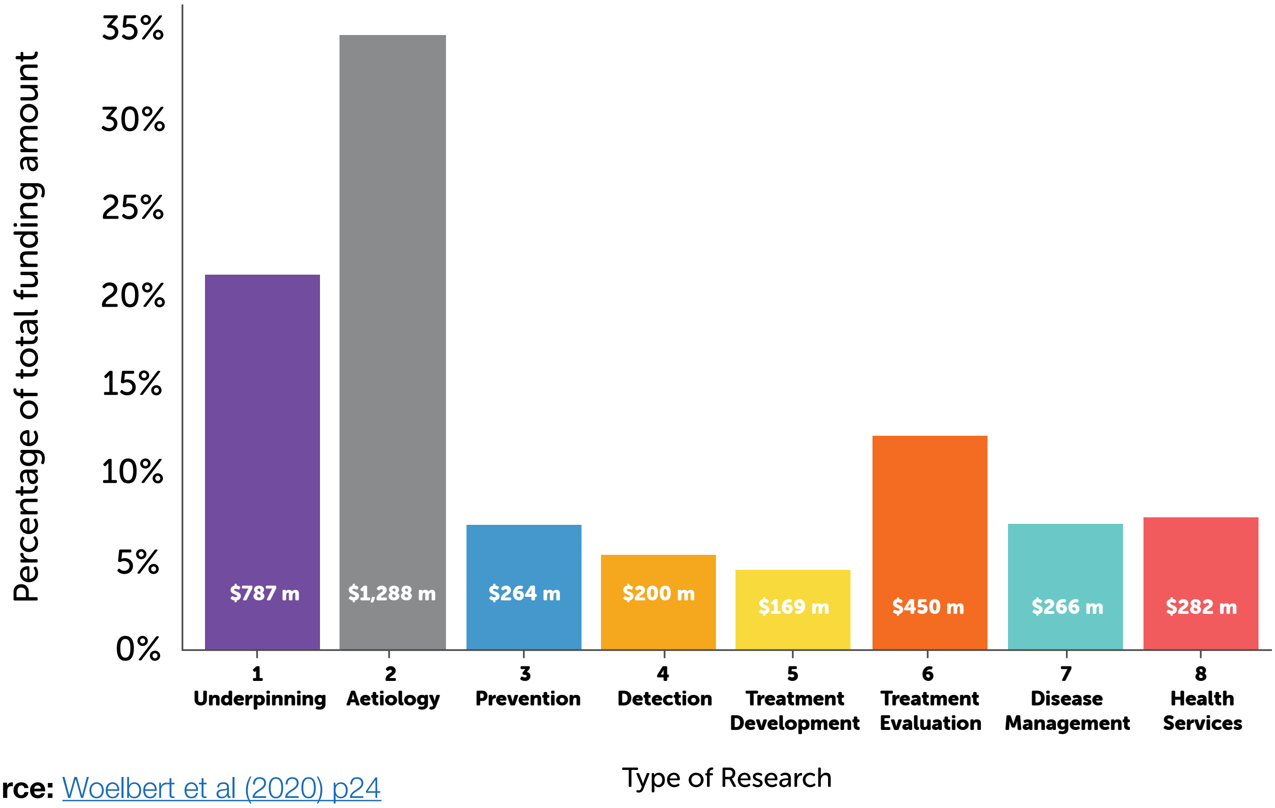
The majority of global mental health research investment is on basic research, rather than prevention or clinical/applied research (graph 3) and despite the anticipated long-term benefits of intervening when people are young, most global mental health research investment is focused on adults. Again, Australia and New Zealand reflect the same mental health research investment distribution (graph 4).

Graph 3: Annual global investments in mental health research by Research Activity Code (RAC)



Source: Woelbert et al (2020) p24

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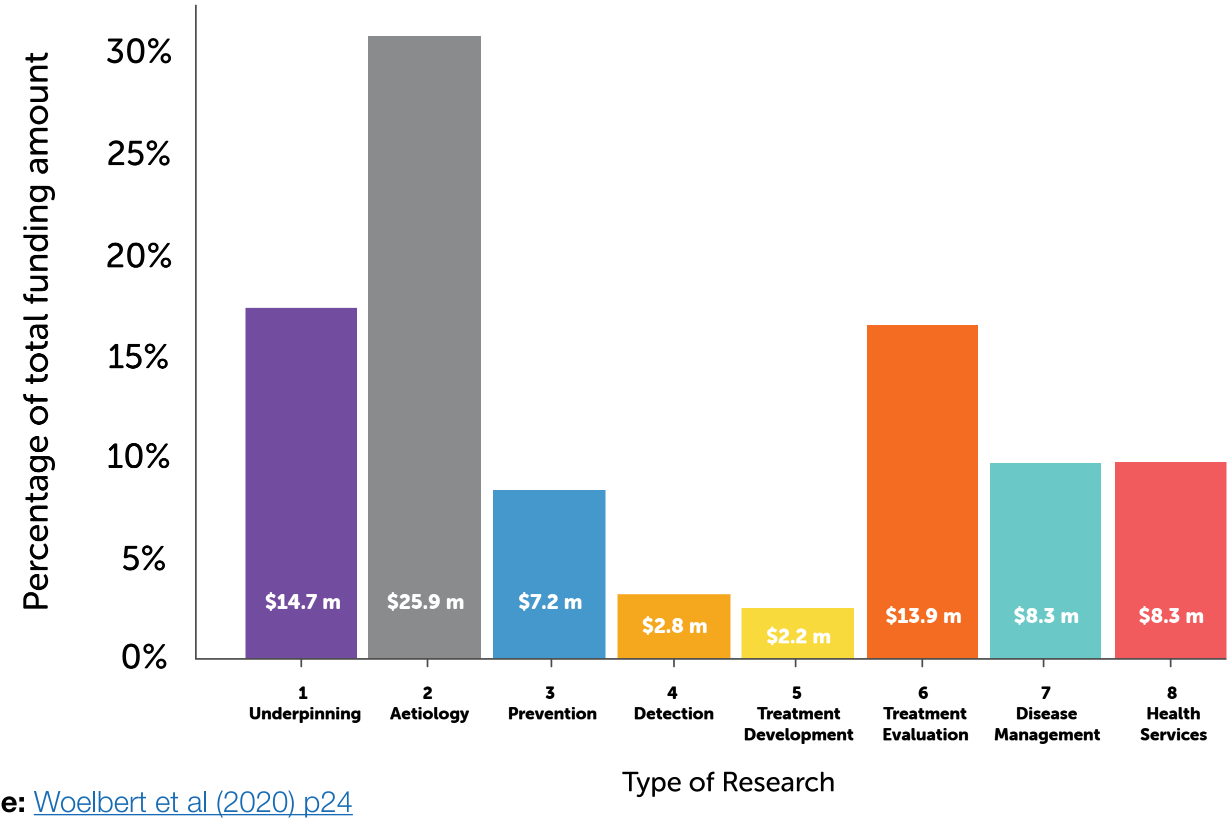
Graph 4: Annual Australian & New Zealand investments in mental health research by Research Activity Code (RAC)



Source: Woelbert et al (2020) p24

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Australian eating disorders research funding

Funding for eating disorder research in Australia reflects the international picture.

Combining funding data with data on population prevalence allows assessment as to whether research funding is going towards areas for which it is most needed.

Numerous independent analyses comparing research dollar investment in eating disorders with other mental disorders have shown that in Australia, eating disorders have consistently had one of the lowest research dollar spends per affected individual of all the major mental illnesses – and they have been under-represented among successful medical research applications, particularly relative to disease impact and burden [85].

Murray et al 2017 – World Psychiatry [1]

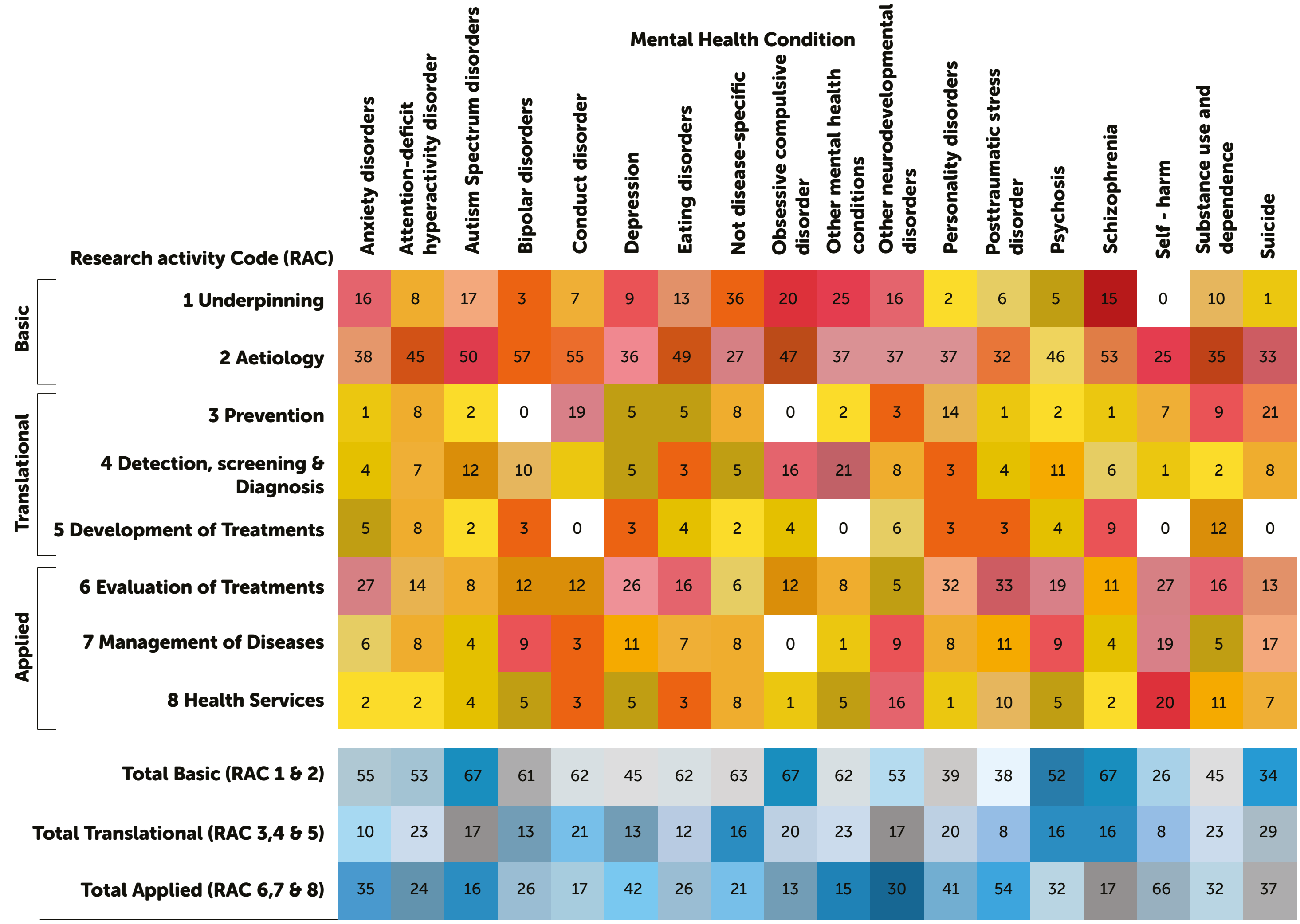
Following global trends, 2017 estimates placed investment for eating disorder research in Australia at approximately $1.10 per affected individual, compared with $32.62 per individual into autism research and $67.36 per affected individual for schizophrenia research and over $100 for the depressive illnesses, despite the fact that the cost burden of eating disorders is comparable with depression [2] [26] [110].

Productivity Commission 2019 [106]

The Productivity Commission's 2019 inquiry into Mental Health identified that there has been no government funding for eating disorder prevention programs since 2011 [106], yet the difference in treatment costs (both economic and social) between therapy delivered early in the illness trajectory and a late-stage response, resulting in hospitalisation, is significant [96].

Table 4 shows regional investment in the different types of eating disorder research and demonstrates the strong focus on basic research, and the limited focus on translational research or applied research.

Table 4: Cross tabulation of the percentage of funding of different mental health conditions by Research Activity Code (RAC)



		Mental Health Condition																	
	Research activity Code (RAC)	Anxiety disorders	Attention-deficit hyperactivity disorder	Autism Spectrum disorders	Bipolar disorders	Conduct disorder	Depression	Eating disorders	Not disease-specific	Obsessive compulsive disorder	Other mental health conditions	Other neurodevelopmental disorders	Personality disorders	Posttraumatic stress disorder	Psychosis	Schizophrenia	Self - harm	Substance use and dependence	Suicide
Basic	1 Underpinning	16	8	17	3	7	9	13	36	20	25	16	2	6	5	15	0	10	1
	2 Aetiology	38	45	50	57	55	36	49	27	47	37	37	37	32	46	53	25	35	33
Translational	3 Prevention	1	8	2	0	19	5	5	8	0	2	3	14	1	2	1	7	9	21
	4 Detection, screening & Diagnosis	4	7	12	10		5	3	5	16	21	8	3	4	11	6	1	2	8
	5 Development of Treatments	5	8	2	3	0	3	4	2	4	0	6	3	3	4	9	0	12	0
Applied	6 Evaluation of Treatments	27	14	8	12	12	26	16	6	12	8	5	32	33	19	11	27	16	13
	7 Management of Diseases	6	8	4	9	3	11	7	8	0	1	9	8	11	9	4	19	5	17
	8 Health Services	2	2	4	5	3	5	3	8	1	5	16	1	10	5	2	20	11	7
	Total Basic (RAC 1 & 2)	55	53	67	61	62	45	62	63	67	62	53	39	38	52	67	26	45	34
	Total Translational (RAC 3,4 & 5)	10	23	17	13	21	13	12	16	20	23	17	20	8	16	16	8	23	29
	Total Applied (RAC 6,7 & 8)	35	24	16	26	17	42	26	21	13	15	30	41	54	32	17	66	32	37

Source: Woelbert et al (2020) p25

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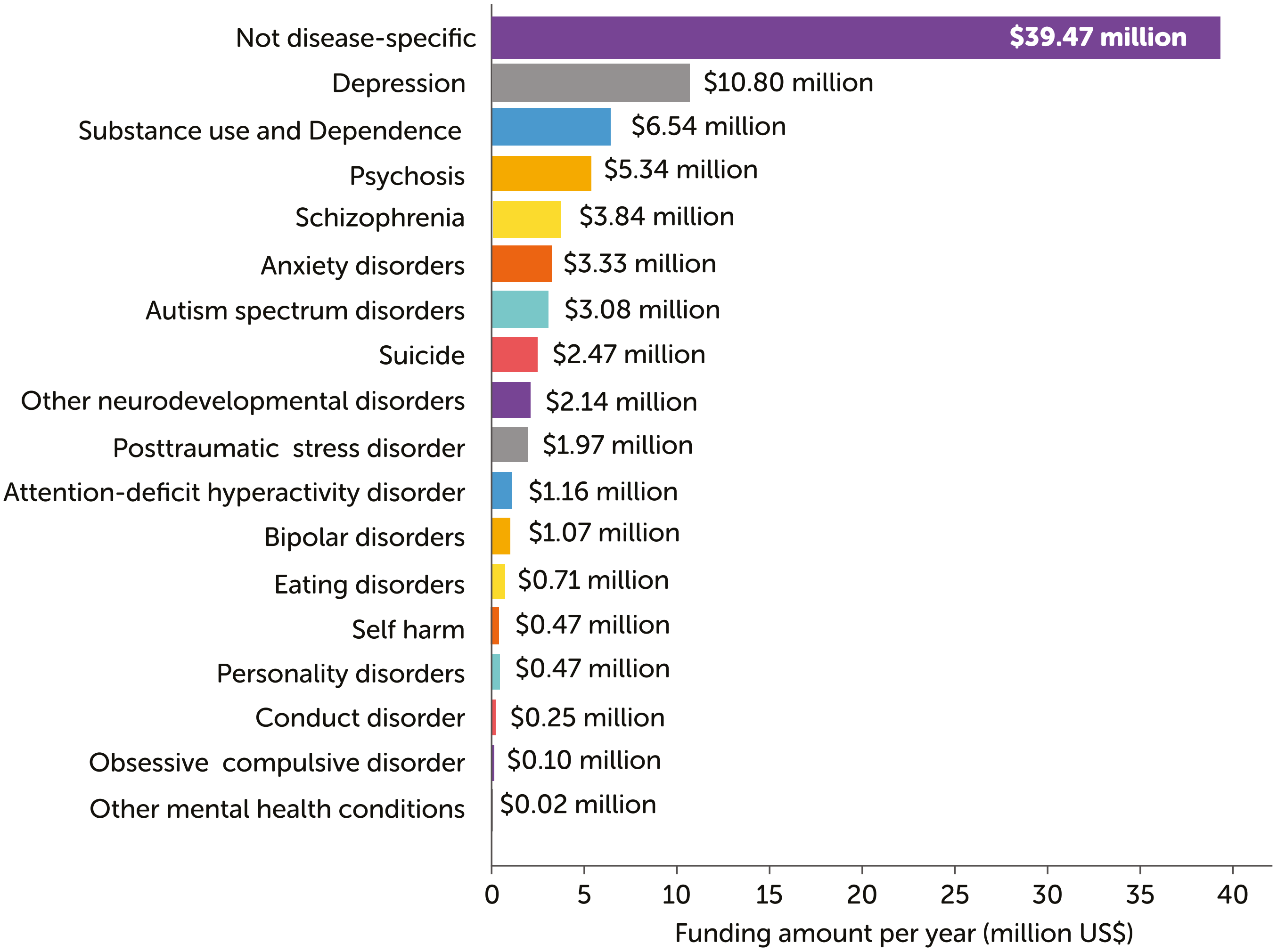
Woelbert et al 2020 – IAMHRF [155]

The 2020 Inequities in Mental Health Research report produced by the International Alliance of Mental Health Research Funders [155] again demonstrated certain fields of mental health research, both globally and in Australia, are consistently underfunded compared to others – specifically, self-harm and suicide, eating disorders, conduct disorder, obsessive-compulsive disorder and personality disorders (graph 5).

Graph 5: Australia & New Zealand investments in mental health research by condition



Source: Woelbert et al (2020) p22

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Updated Analysis 2021

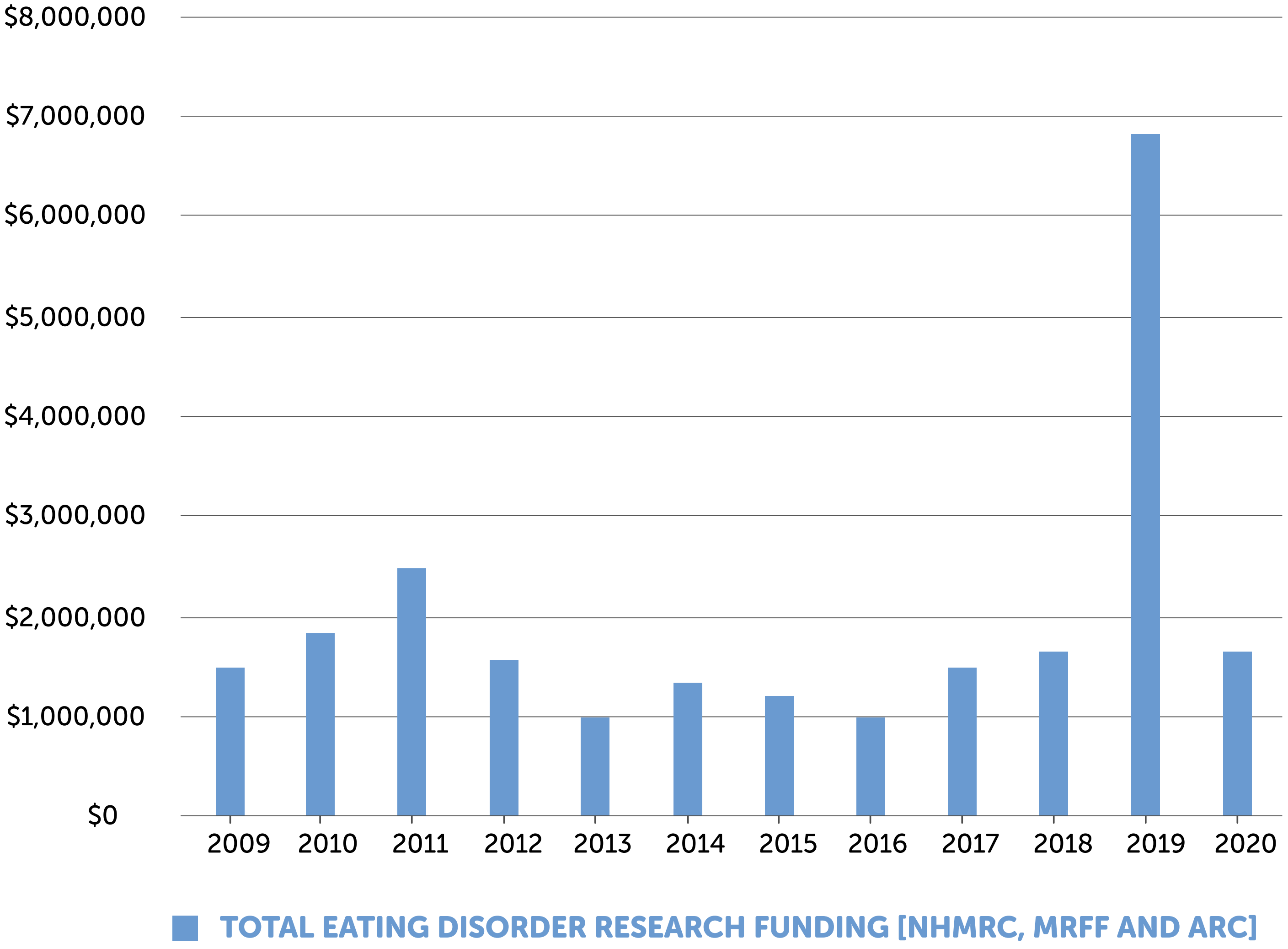
In the development of this Strategy a retrospective portfolio analysis of total funding levels by illness group was conducted using data obtained from the National Health and Medical Research Council (NHMRC) data analysts, and for other funding sources through independent keyword analysis of publicly available Medical Research Future Fund (MRFF) [260] and Australian Research Council (ARC) [261] datasets. Descriptive analyses of total awarded funding for the years 2009-2020 was cross-tabulated by illness group and official point prevalence rates reported by the Australian Bureau of Statistics where available (Major Depressive Disorder – 4.2%, and Anxiety Disorders – 14.4% [262]) and the Department of Health for other illness groups (Autism – 0.7% [263] and Schizophrenia – 0.24% [264]). Where such data does not exist (Eating Disorders), a point prevalence rate of approximately 4.5% was ascertained from large epidemiological studies and reports [5] [125].

The average research spend per affected individual for the twelve years to and inclusive of 2020 was $1.71 for eating disorders, $5.08 for the anxiety disorders, $19.81 for depression, $23.89 for autism, and $197.14 for schizophrenia.

Of note, the Million Minds Mental Health Research Mission (Million Minds) was announced by the Commonwealth government in the 2018-19 budget to support innovative and ground-breaking mental health and suicide prevention research. Initial funding priorities included people with eating disorders, child and youth mental health, and Aboriginal and Torres Strait Islander mental health. Reflecting the value of a co-design approach to research at all stages, the Million Minds program aims to enable people who might not otherwise benefit from research and trials to take part and be part of the solutions, especially smaller organisations, individuals with lived experience, and early career researchers. The program commenced in 2018-19 with $5m specifically allocated to eating disorder research, representing the first significant investment in eating disorder research in Australia.

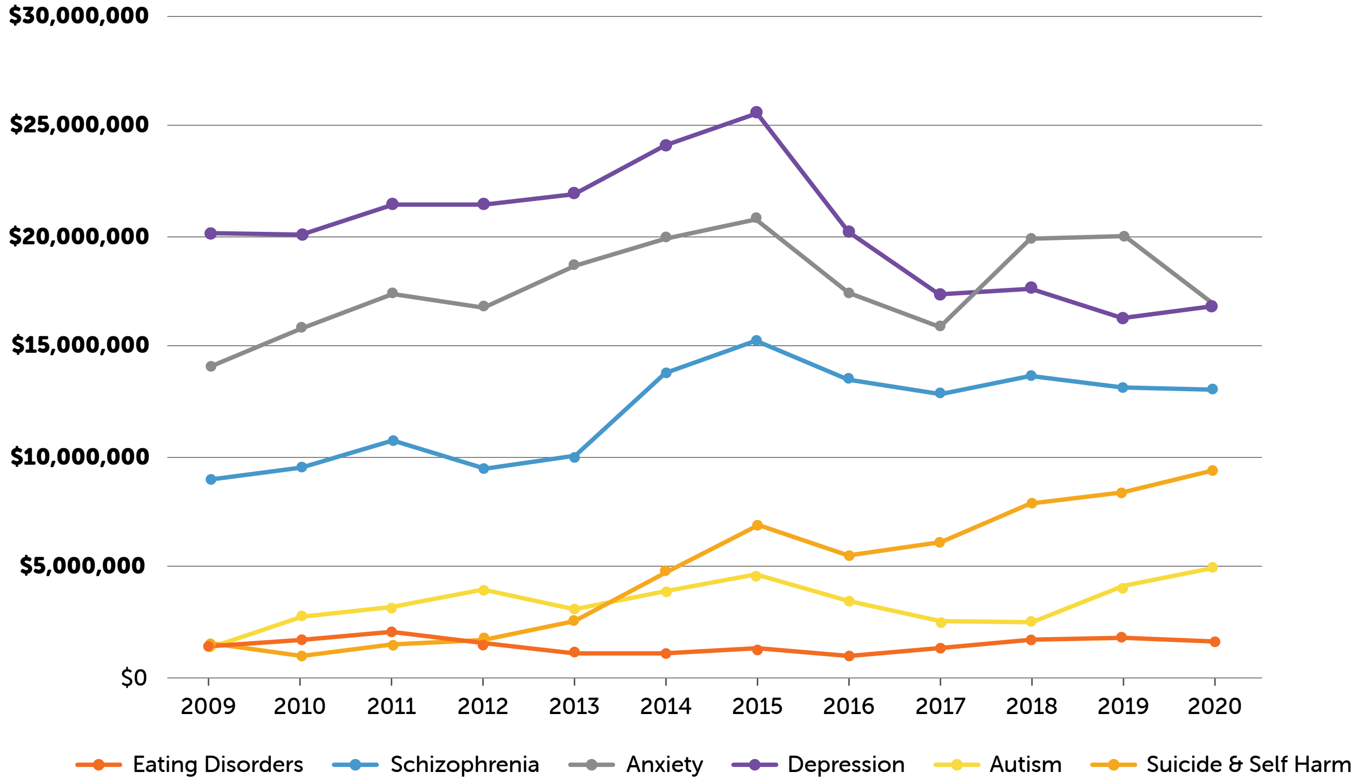
Graph 6 shows total government funding for eating disorder research through primary schemes including National Health & Medical Research Council (NHMRC) grants (including the Medical Research Future Fund scheme) and Australian Research Council (ARC) grants (a breakdown of which can be seen in tables 5-7 pp51-52). Note that 2019 saw the only targeted research call (of $AUD 5m) for eating disorders in Australia to date.

Graph 6: Eating Disorder Research Funding in Australia 2009-2020



Graphs 7 & 8 show the NH&MRC funding expenditure by mental health disorder across the period 2009-2020, and the percentage of the total NH&MRC mental health expenditure, which demonstrates the comparatively low rates of investment in eating disorder research compared with other mental illnesses.

Graph 7: National Health & Medical Research Council Expenditure by disorder 2009-2020.



Graph 8: National Health & Medical Research Expenditure 2009-2020 – percentage of total mental health spend by disorder.

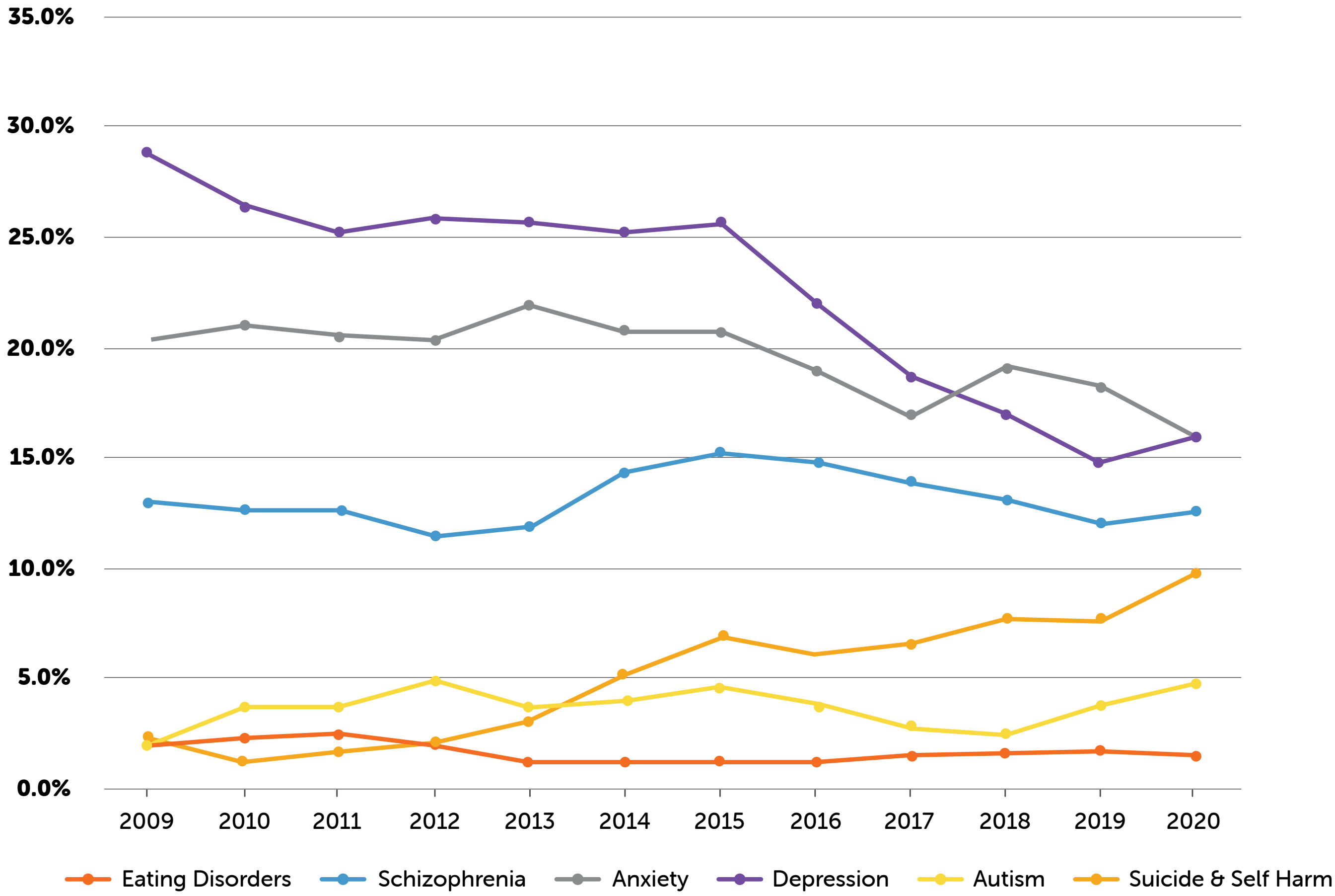


Table 5: National Health & Medical Research Council Mental Health Funding 2009-2020 for selected mental disorders

Category	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
TOTAL MENTAL HEALTH FUNDING EXPENDITURE	**$69,439,372**	**$75,250,080**	**$84,605,539**	**$82,271,951**	**$84,961,598**	**$95,835,505**	**$100,010,58**	**$91,129,544**	**$93,250,**	**$103,980,196**	**$109,504,381**	**$103,800,000**
Eating Disorders funding % of total MH Funding	$1,418,422 2%	$1,715,216 2.3%	$2,025,676 2.4%	$1,532,964 1.9%	$1,054,457 1.2%	$1,055,633 1.1%	$1,284,207 1.2%	$967,488 1.1%	$1,355,093 1.4%	$1,697,244 1.6%	$1,766,063 1.6%	$1,599,835 1.5%
Schizophrenia funding % of total MH funding	$8,967,705 13%	$9,478,852 12.6%	$10,680,212 12.6%	$9,452,669 11.5%	$10,010,561 11.8%	$13,754,257 14.3%	$15,220,295 15.2%	$13,472,919 14.8%	$12,864,947 13.8%	$13,646,370 13.1%	$13,115,210 12%	$13,070,023 12.6%
Autism funding % of total MH funding	$1,347,895 1.9%	$2,716,451 3.6%	$3,171,788 3.7%	$3,895,100 4.7%	$3,046,952 3.6%	$3,888,241 4%	$4,582,923 4.6%	$3,427,440 3.8%	$2,532,342 2.7%	$2,512,112 2.4%	$4,052,882 3.7%	$4,936,104 4.8%
Anxiety funding % of total MH funding	$14,134,445 20.3%	$15,758,855 20.9%	$17,327,753 20.5%	$16,719,573 20.3%	$18,627,106 21.9%	$19,891,336 20.7%	$20,704,312 20.7%	$17,351,539 19%	$15,837,154 17%	$19,872,764 19.1%	$20,128,744 18.3%	$16,758,106 16.1%
Depression funding % of total MH funding	$20,023,692 28.8%	$19,939,631 26.5%	$21,332,598 25.2%	$21,345,533 25.9%	$21,815,887 25.7%	$24,081,919 25.1%	$25,461,839 25.5%	$20,074,043 22%	$17,308,446 18.6%	$17,603,564 16.9%	$16,296,479 14.8%	$16,849,769 16.2%
Suicide and Self Harm % of total MH funding	$1,574,889 2.3%	$919,522 1.2%	$1,470,423 1.7%	$1,725,092 2.1%	$2,593,942 3%	$4,761,536 5%	$6,870,179 6.8%	$5,535,484 6.1%	$6,112,876 6.5%	$7,922,730 7.6%	$8,349,507 7.6%	$9,321,187 9.8%
Adolescent Health % of total MH funding	$15,964,286 23%	$17,740,294 23.6%	$20,774,866 24.5%	$21,550,616 26.2%	$22,671,530 26.7%	$23,503,752 24.5%	$26,162,453 26.1%	$20,298,811 22.3%	$18,919,776 20.3%	$20,222,732 19.4%	$21,715,584 19.8%	Not provided

Table 6: Australian Research Council - Eating Disorders Grants 2009-2020

2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
$0	$214,000	$506,247	$0	$0	$360,000	$0	$0	$273,000	$0	$0	$426,925

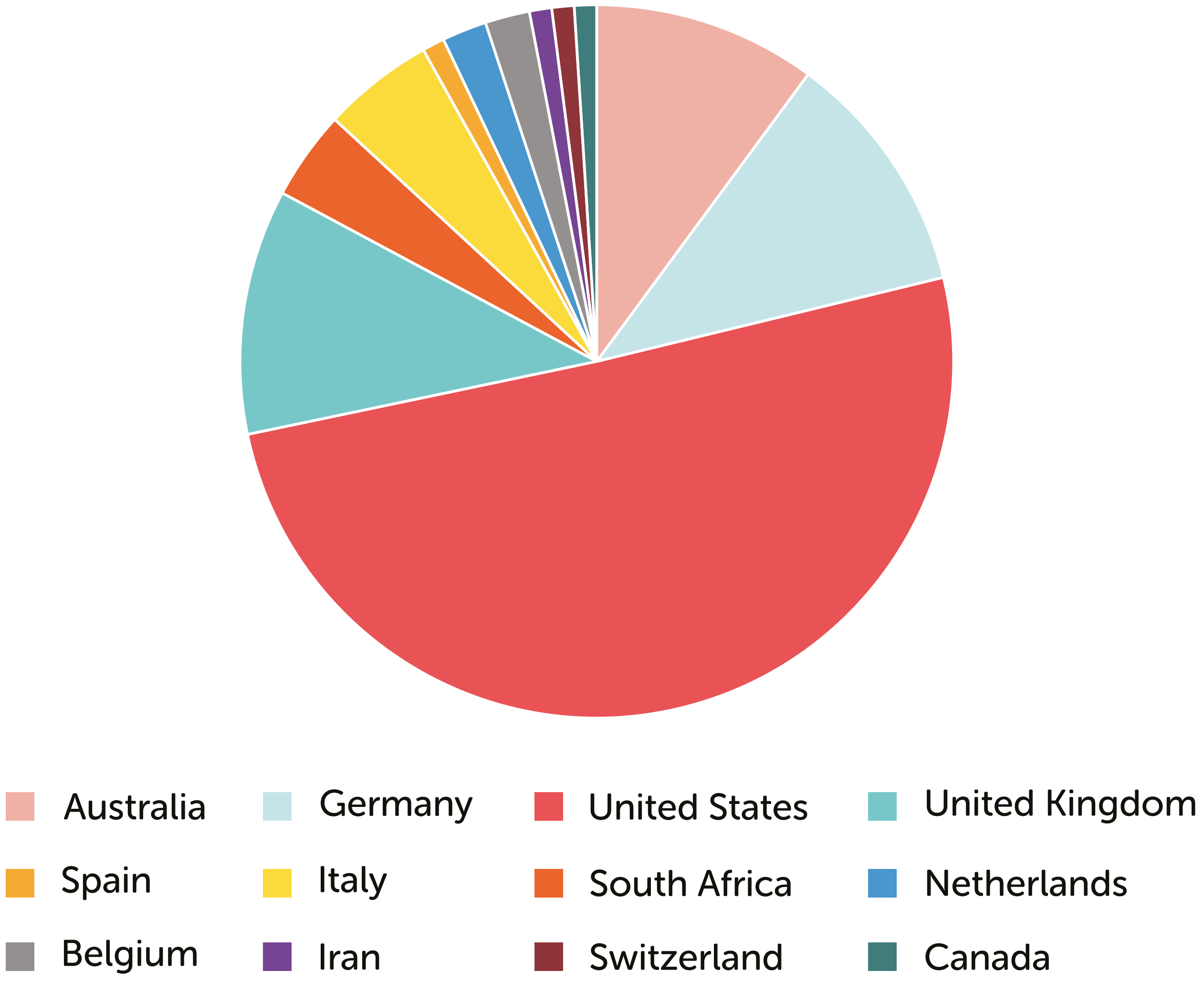
Table 7: Million Minds Mental Health Research Fund - Eating Disorders Grants 2019-2020

	2018	2019	2020
	$0	$$5,012,948	$0

Australian eating disorders research

Despite the paucity of funding, Australian researchers have made a significant contribution to the global knowledge base around eating disorders – in fact, of the top 100 ranked eating disorders researchers in the world (based on ‘eating disorder’ publications from 1990-2021), Australia ranks fourth (graph 9 below).

Graph 9: Country of origin of the top 100 ranked eating disorder researchers by publications 1990-2021

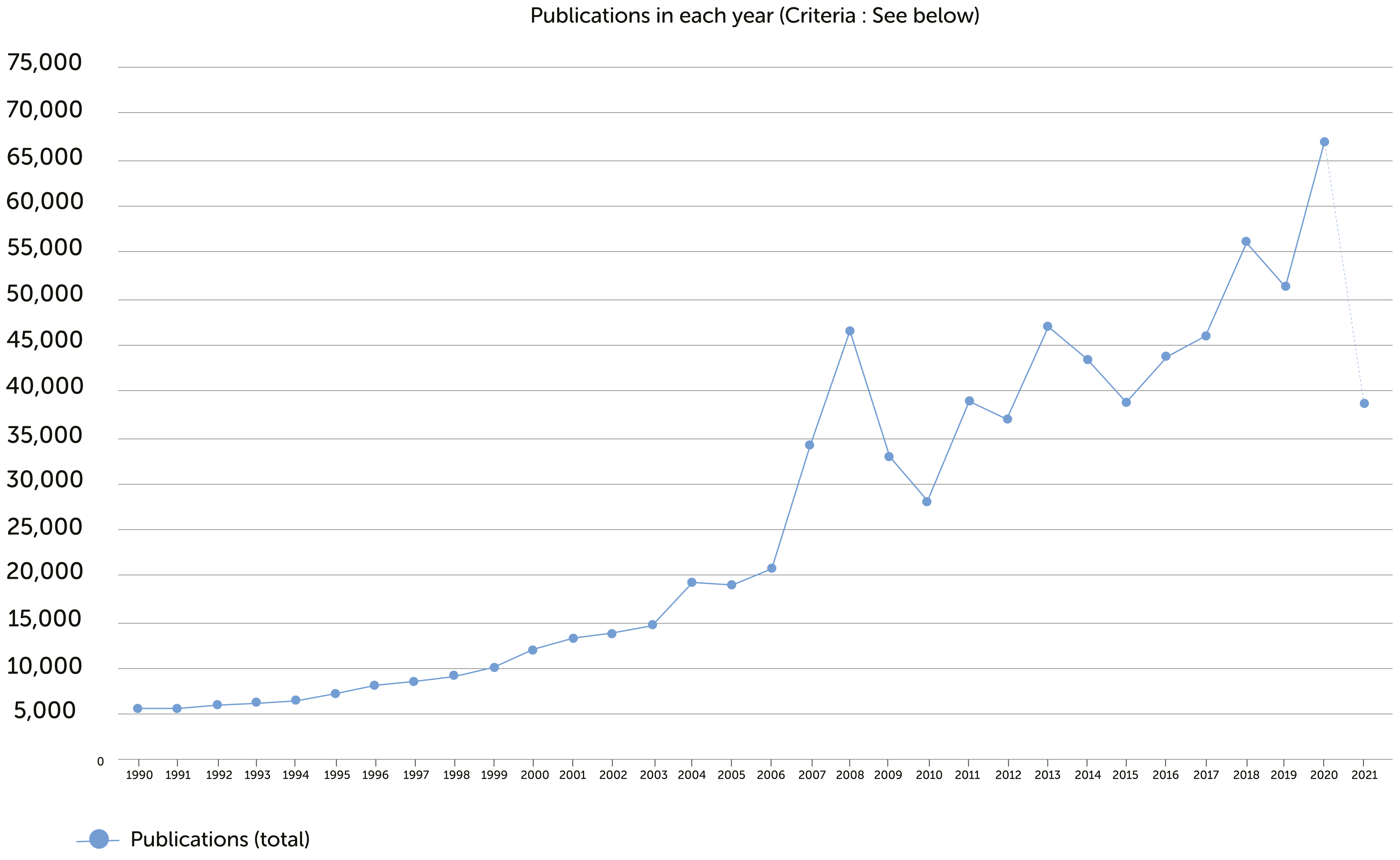


Source: Dimensions http://app.dimensions.ai

Australian researchers have contributed to the knowledge base relating to sociocultural risk factors for body dissatisfaction and eating disorders; the development of body image attitudes in children; epidemiology of eating disorders; genetic underpinnings of eating disorders; prevention and early intervention strategies; and eating disorder treatments. Australian carer research is also significant. Australian researchers also contribute to the international research knowledge base by participating in multi-site research programs – both with services and institutions in Australia and overseas.

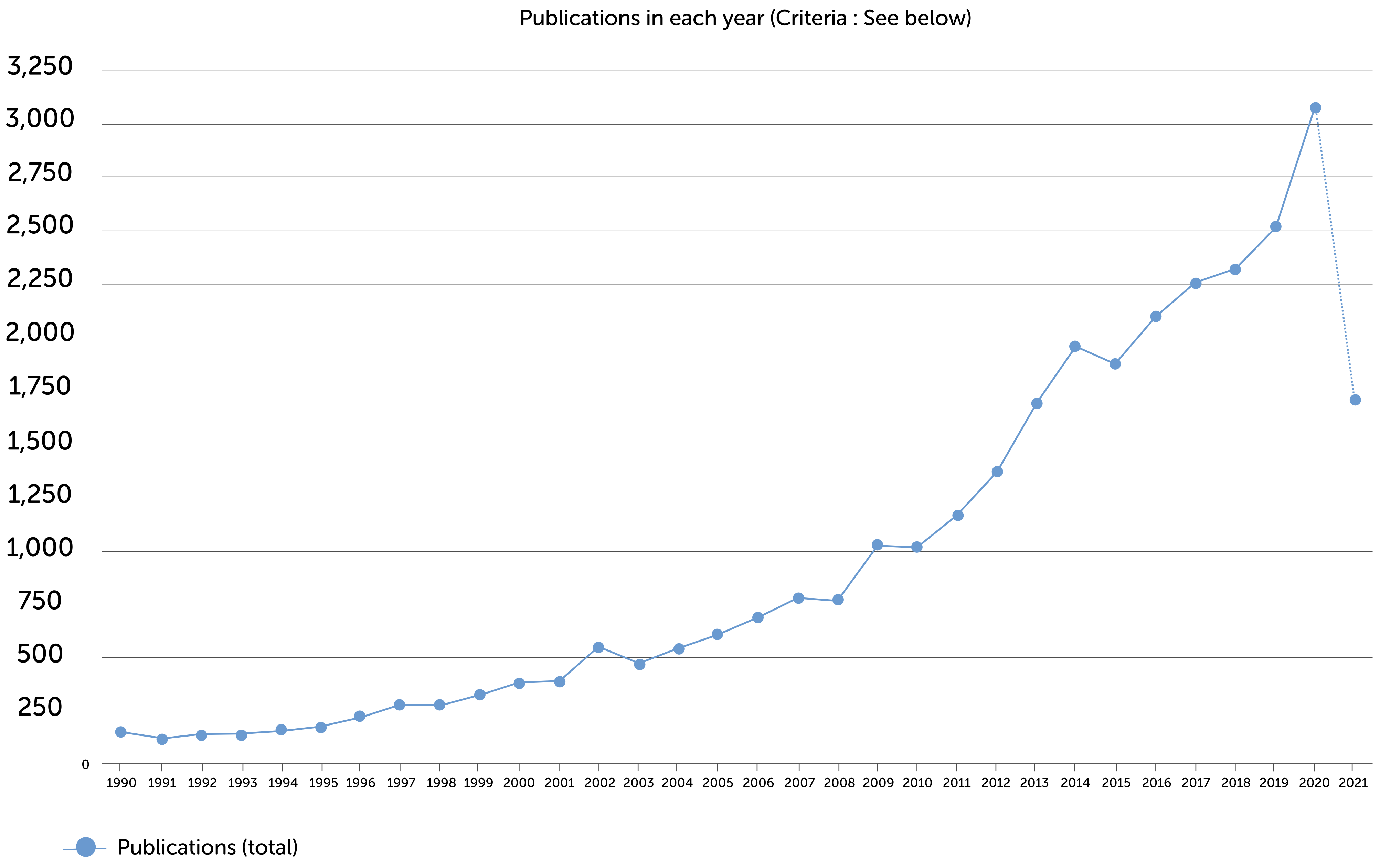
Australian research publication volume has followed international trends (graph 10 and graph 11), with significant increase in publications from 2000 onwards. However, it is clear that a significant amount of unfunded research is occurring – graph 12 (below) identifies eating disorder publications in Australia (1990-2020) that were funded – in 2019 for example, just over 18% of all publications were identified as being from funded eating disorder research.

Graph 10: Eating disorder publications worldwide 1990-2021



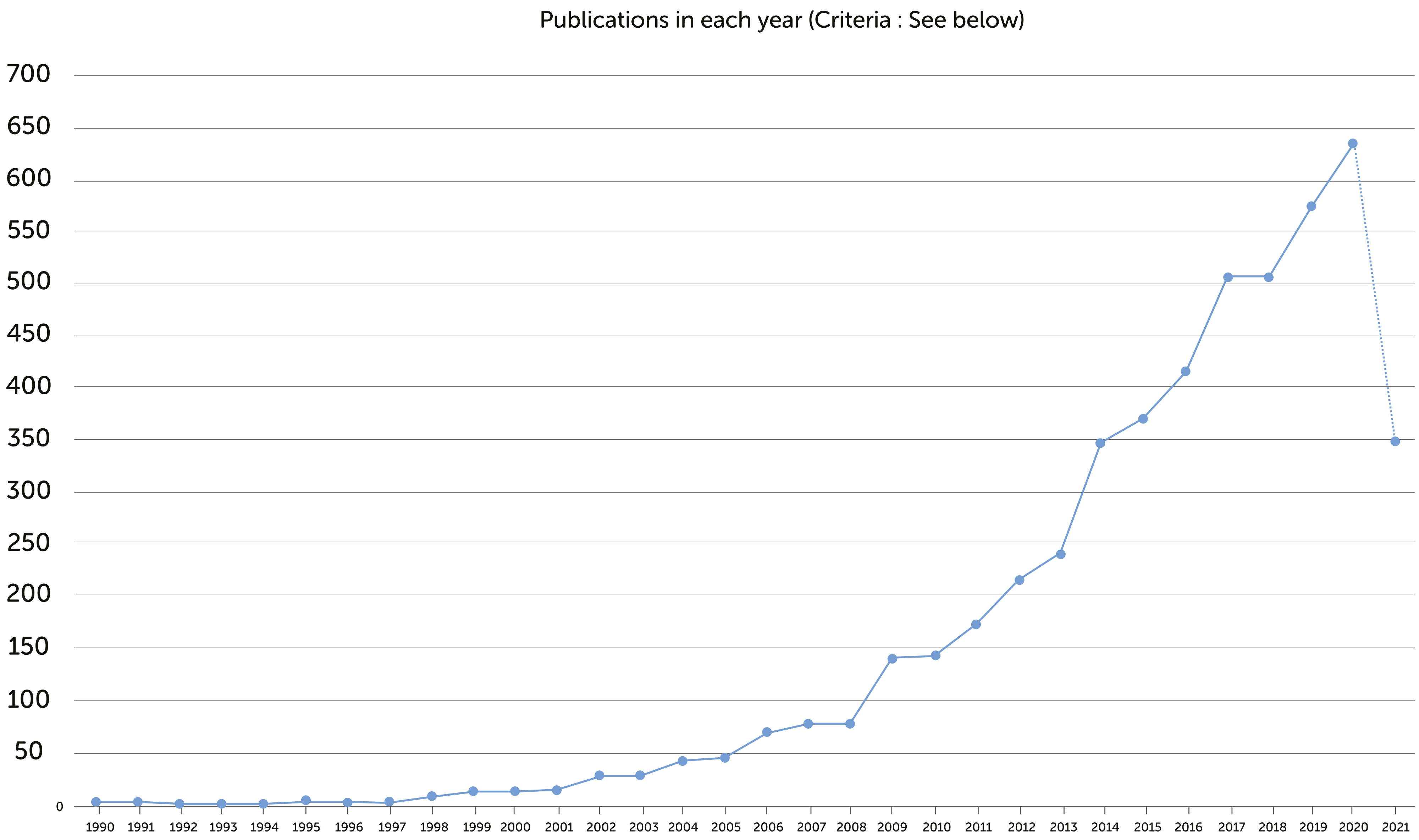
Source: Dimensions http://app.dimensions.ai

Graph 11: Eating Disorder publications in Australia 1990-2021



Source: Dimensions http://app.dimensions.ai

Graph 12: Funded Eating Disorder research publications in Australia 1990-2021



Source: Dimensions http://app.dimensions.ai

Australian research institutions have established significant expertise in specific areas of eating disorders research. Table 9 (below) shows the ranking of Australian research institutions [identified through Expertscape] as indexed by eating disorders publications (2010-2021) for four of the eating disorder diagnoses.

Table 9: Ranking of Australian research institutions by eating disorder publications 2010-2021

	AN	BN	BED	ARFID
Austin Health	5			
Australian Catholic University		6	10	
Curtin University		9		
Deakin University		3	2	8
Flinders University		2	8	3
Macquarie University		10	4	
Miscellaneous institutions in Melbourne	9			
Miscellaneous institutions in Perth		8		
Miscellaneous institutions in Sydney				5
Monash University	7		9	1
Murdoch Children's Research Institute	8			
Queensland University of Technology				9
Royal Children's Hospital	8			
Royal North Shore Hospital				10
Swinburne University	4			
St Vincent's Hospital Melbourne	6			
University of Adelaide				2
University of Melbourne	1	4	6	
University of New South Wales			5	
University of Sydney	2	5	3	7
University of Western Australia		7	7	
Western Sydney University	3	1	1	4
Westmead Hospital	10			6

AN: Based on 374 articles published 2010-2021; **BN:** Based on 125 articles.
BED: Based on 126 articles; **ARFID:** Based on 19 articles.
Source: Expertscape **Note:** Expertscape utilises the PubMed database as its source
Date: 14 August 2021

Table 10 shows the affiliated Australian research institutions [identified through Dimensions] of the 100 most published eating disorder researchers in Australia (2010-2021). The top five most published Australian academics over that period are from Western Sydney University (Rank 1), The University of Sydney (Rank 2), Flinders University (Rank 3 and 4) and the University of Tasmania (Rank 5).

Table 10: The Australian research institution affiliation of the top 100 Australian eating disorder researchers as indexed by publications (2010-2021).

Australian Catholic University, Australia	1
Australian National University, Australia	3
Curtin University, Australia	4
Deakin University, Australia	5
Griffith University, Australia	2
Government of Western Australia Department of Health, Australia	1
Flinders University, Australia	3
La Trobe University, Australia	3
Macquarie University, Australia	2
Monash University, Australia	7
Murdoch Children's Research Institute, Australia	2
University of Adelaide, Australia	3
University of Melbourne, Australia	10
University of Newcastle Australia, Australia	11
University of Queensland, Australia	3
UNSW Sydney, Australia	6
University of Sydney, Australia	17
University of Tasmania, Australia	1
University of Western Australia, Australia	4
University of Wollongong, Australia	1
QIMR Berghofer Medical Research Institute, Australia	1
Queensland University of Technology, Australia	1
Royal North Shore Hospital, Australia	1
Swinburne University of Technology, Australia	4
Western Sydney University, Australia	2
Westmead Hospital, Australia	2
	100

Source: Dimensions http://app.dimensions.ai

Knowledge base and current evidence gaps

A strong evidence base provides the framework for the development of programs, services and policy interventions to address populations at risk. Understanding the scope of existing research allows us to focus our exploration on any evidence uncertainties.

As part of the development of this Strategy, InsideOut Institute commissioned Healthcare Management Advisors Australia (HMA) to produce a Rapid Review of the literature on eating disorders. A Rapid Review is systematic in nature, largely adheres to the PRISMA guidelines for systematic evidence reporting and is frequently conducted using broad search terms and inclusion criteria, attempting to understand a field of study in its entirety. Rapid Reviews typically drive evidence for decision-making processes in order to address high-priority or urgent health concerns [156].

The Rapid Review will be published as a set of papers in a special edition of the Journal of Eating Disorders from late 2021. Below, are some of its key findings and areas in which further research is needed.

Population prevalence, disease burden and quality of life

There is a significant body of evidence relating to eating disorder prevalence, incidence, mortality, burden of disease and quality of life.

Global lifetime prevalence of any eating disorder for females is currently 8.4% and 2.2% for males [157] with most illness on-set between the ages of 20 and 30 [158] [159] [87]. Age of onset is demonstrably getting younger [160] [161]. However, these prevalence estimates are consistently confounded by: the relatively small number of population studies done in Australia (and very few in populations aged over 40), variations in methodological design, diagnostic heterogeneity, and limited evidence on broad eating disorder diagnostic groups including OSFED, ARFID and UFED [162] [163] [164].

Preliminary research suggests minority populations such as Aboriginal and Torres Strait Islanders and LGBTQI+ individuals may be at higher risk of developing an eating disorder [165] [52]. There is also growing recognition of the impact of eating disorder in males. It is estimated that one in four pediatric patients in Australia presenting to an eating disorder service is male [166]. Further research on all of these populations is needed.

Disease burden and quality of life in eating disorders is under-researched and confounded by the use of variable metrics in their assessment. A systematic analysis of data from 195 countries from 1990–2017 found that the global disease burden for any eating disorder was 43.4 age-standardised Disability Adjusted Life Years (DALYs) per 100,000. Between 2007 and 2017, global disease burden caused by eating disorders increased by 9.4% [167].

The economic cost of eating disorders in Australia is widely reported to be $69.7billion [125]. The annual societal cost of treating just one individual with AN in Australia was reported in one study to be $20,000 [168]. However, economic studies have typically yielded very small sample sizes. Further research is needed to understand the economic burden of eating disorders at a national level.

While Health Related Quality of Life (HRQoL) is typically shown to be significantly impaired in individuals with eating disorders [49] [169] [170] evidence is mixed. Researchers have pointed to the use of generic measures and assessment tools, which are insufficient to detect the unique features present in eating disorders [171] including the insensitivity of self-report HRQoL measures to the egosyntonic nature of AN - as a possible reason for conflicting findings.

Risk factors

A range of risk factors have been identified in the literature relating to the onset of eating disorders. Development of an eating disorder is multi-factorial and highly dependent on the individual. Understanding the range of risk factors and their potential contribution to onset of eating disorders is central to identifying at-risk groups and providing effective screening and prevention programs, as well as targeted treatment.

Known risk factors for BN and BED include childhood abuse or trauma, body dissatisfaction and childhood obesity [172] and for AN: thin-ideal internalization [173] anxious, perfectionistic, and obsessional traits and emotional dysregulation [174] [175] [176] [177] [178]. There is very little research on risk factors for the other eating disorders.

There are two significant emerging areas in the study of risk factors: genetic studies and the impact of the gut microbiota and immune system. Large scale genomic studies have indicated a genetic component to risk of AN, BN and BED [179].

Evidence of genetic risk factors for other eating disorders are also growing [180]. A recent meta-analysis of 33 datasets from international genome-wide association studies identified eight loci associated with significant risk of developing AN [181].

Genetic susceptibility to binge eating behaviours has also been found across BN and BED. One study identified six genetic polymorphisms associated with the development of BN in people living in larger bodies [182].

These emerging areas may prove potential targets for treatment.

Prevention and early intervention

Rapid response following onset is considered particularly important given eating disorders become more difficult to treat as they progress and are increasingly complicated by physical and mental health comorbidity [183].

There is a considerable amount of evidence relating to prevention programs for eating disorders, particularly as part of school or university-based programs, with growing evidence around the use of technology, mindfulness, and self-help. Prevention programs for eating disorders (including cognitive dissonance based, school-based and mindfulness-based programs) demonstrate good efficacy, showing up to 51% reduction in at least one eating disorder risk factor [59].

Selective prevention interventions aimed at high-risk groups including females and adolescents over the age of 15 and delivered by professionals may be most effective. Further, delivery of web-based and obesity prevention programs could be effective in the prevention of binge/purge type disorders (BN and BED) [59].

Favourable outcomes are associated with early intervention and rapid response to treatment, however, very little research has been conducted on early intervention programs in eating disorders. Preliminary evidence suggests early intervention may be enhanced by helping parents recognise early signs of an eating disorder during peak time of onset in adolescence [184], delivering programs that increase motivation to change among people with eating disorders [185], and addressing stigma and shame. First-aid training has also been found to increase the confidence of members of the public to approach people exhibiting eating disorder symptoms and behaviours, encouraging them to seek help [186] [187].

There is a need to replicate and scale-up successful prevention and early intervention programs as well as identify any potential barriers to wider dissemination [188].

While there is a significant knowledge base for effective eating disorder prevention and experience in delivering trials, there remains a lack of translation to clinical and practical settings, partially due to lack of funding prioritisation [189].

Capacity to increase the reach of eating disorder prevention and early intervention programs will be critical to reducing the public health burden of eating disorders [190].

Screening and diagnosis

Primary health practitioners play a pivotal role in the early identification and diagnosis of people with eating disorders in the community, providing those affected with timely access to care and, ideally, early intervention [52] [191]. As such, there is enormous potential for clinical utility in undertaking screening for eating disorders in primary care settings [192]. However, there is little indication that screening is occurring appropriately in Australia, or that most healthcare professionals know how to correctly diagnose an eating disorder [193] [194]. Further, the capacity of existing screening tools to capture all DSM-5 eating disorders in this setting has been questioned by researchers who indicate that potential cases may be over- or under-diagnosed [195].

The review found a need for increased screening for eating disorders in all primary care settings but particularly in high-risk groups, including women seeking reproductive healthcare, adolescents with diabetes and individuals (over 25) with high Body Mass Index (BMI) experiencing significant weight gain in the past year. People with high BMI experiencing significant weight loss should also be screened for eating disorders.

Recognising the higher risk and elevated prevalence of eating disorders among adolescents and young adults, almost all screening program studies have been conducted in high school or university student samples. Despite eating disorders being commonly associated with mental health comorbidities, they are rarely assessed when people seek treatment for other conditions [196]. Given the elevated rates of eating disorders among people seeking broader mental health and psychiatric services, researchers have suggested that screening for eating disorders should be built into routine assessments [197].

A considerable proportion of people meeting diagnostic criteria for an eating disorder, or displaying problematic disordered eating behaviours, do not seek treatment [198] [87]. Currently, only 1 in 4 individuals seeks treatment [199].

Clinicians report particular difficulty identifying certain groups with eating disorders, including children and men, who tend to exhibit less stereotypical symptomology than adolescents and therefore have a potential to be overlooked. Further, due to the heterogeneity and relative newness of diagnostic categories ARFID, OSFED and UFED, people experiencing these disorders are frequently not identified. Clinical education and the need for improved screening tools, for a broad range of eating disorder symptomatology, is strongly indicated.

Comorbidities and medical complications

Research consistently demonstrates high comorbidity between eating disorders and anxiety or mood disorders [38, 200] [201]. Studies show up to 71.5% of people with an eating disorder have at least one comorbid mental health disorder [38]. Identifying comorbidities is critical to treatment and management as they are known to contribute to eating disorder symptom severity and psychological distress, as well as the effectiveness of the therapeutic journey [202, 203].

Eating disorder treatment efforts are particularly hampered by comorbidity, with personality disorders [203] contributing to poorer outcomes [204]. Research indicates that treatment targeting both anxiety and eating disorder symptoms could lead to better outcomes [205].

There is emerging evidence of comorbid links between certain eating disorders and Attention-Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) [206] [207] [208] [209], however, further research is needed in these areas.

A significant proportion of literature relating to medical management of people with eating disorders relates to treating loss of bone density and refeeding in people with AN. Known medical complications of eating disorders include (but are not limited to) liver, gastrointestinal and cardiac abnormalities [210], tooth erosion and periodontal disease [211] [212], infertility and PCOS [199] [213]. However, most of the literature relating to medical complications of eating disorder has been conducted in AN only. The Rapid Review found a lack of high-quality evidence relating to the management of medical complications arising from other eating disorder presentations including BED and BN. There have been almost no trials on interventions used to manage the medical complications for eating disorders other than AN; the literature is comprised of either guidance documents for clinicians or observational studies.

Psychotherapies and models of care

Psychotherapies are considered central to the effective treatment of eating disorders. Of these, CBT has been the most rigorously scrutinised [214]. However, evidence is mixed as to its effectiveness, particularly in adults [215] [216].

Family-Based Therapy is widely considered to be the most effective treatment for children and adolescents [217] [218] but remains successful in just half of all cases [219] [220]. As such, there has been a proliferation of new ‘third wave’ therapies including Dialectical Behaviour Therapy, Acceptance and Commitment Therapy (ACT), mindfulness-based interventions (MBI), and Compassion-Focused Therapy (CFT) [217].

Other novel approaches, including Cognitive Remediation Therapy (CRT) and Exposure and Response (ERP) therapies, need further research.

To increase access to CBT, online programs have been developed (referred to as iCBT). Research to date, finds that these interventions appear to be efficacious in people with BN or BED in particular. Completion is highly dependent on the person’s motivation and readiness to change. Guided self-help interventions, therefore, may deliver better outcomes than ‘pure’ self-help.

Few studies were identified by the Rapid Review involving patient samples with OSFED, and none with UFED. The literature indicates that work is currently being undertaken to assess the efficacy of FBT and CBT to treat ARFID.

The healthcare settings and types of health professionals involved in the care of a person with an eating disorder are just as important as the effectiveness of the individual intervention delivered. Gaps in services and delayed diagnosis—and subsequently specialist care and treatment—not only leads to poorer health outcomes for the individual but also significant healthcare expenditure. The psychological and financial burden of long hospital stays has prompted a shift from inpatient care to outpatient care; evidence from systematic reviews suggests there is no difference in outcomes between these two modes. The flexibility of stepped care offered by partial hospitalisation programs has demonstrated benefit in a number of studies, but needs further research - as does the impact of healthcare settings and multi-disciplinary teams on eating disorder treatment and outcomes, and how outpatient stepped care models can be better integrated into 'wrap-around services' for people who experience severe and enduring disorders.

Pharmacotherapies and alternative/adjunctive therapies

The evidence-base supporting the effectiveness of pharmacotherapies for the treatment of eating disorders is not as considerable as the evidence-base for psychotherapies. Research indicates that pharmacotherapies are routinely provided to people with AN, despite lack of evidence regarding their efficacy in this population group. Evidence from several large trials shows that central nervous system stimulants are highly effective for people with BED. Evidence from trials on the effectiveness of antidepressants to treat those with BN is significantly dated, much of it derived from the 1990s and early 2000s.

Pharmacotherapy trials typically have small population samples, often without control groups. Few large-scale RCTs have been conducted that seek to assess pharmacotherapies for eating disorders. They also tend to have higher attrition rates than psychotherapy trials [221].

Globally, the most common drugs approved for eating disorder treatment are selective serotonin reuptake inhibitors (SSRIs) and fluoxetine for BN, and a central nervous system stimulant Lisdexamfetamine (LDX) for BED [222]. Research into SSRIs for AN treatment has yielded poor results [223].

Evidence for the use of atypical or 'second generation' antipsychotic medications in AN is mixed. Some studies have found a reduction in depressive, obsessive and compulsive symptoms, and improved weight restoration [224] [222] [221], while others suggest they are no more effective than placebo or treatment as usual (TAU) [225] [226] [227]. Potential targets within the gastrointestinal and associated immunological receptor pathways may represent an opportunity for efficacious pharmacotherapies for AN in future research. However, human studies are yet to be undertaken [222].

There is emerging evidence for the potential of novel psychopharmaceutics in eating disorders including cannabinoid [228], oxytocin [229] [230] [231] and psychedelics [232], however, further research is needed. There is also increasing interest in neuromodulation techniques, specifically Repetitive Transcranial Magnetic Stimulation (rTMS), Deep-Brain Stimulation (DBS), and Transcranial Direct Current Stimulation (tDCS) [233].

Neurostimulation is generally only considered in 'treatment-refractory' cases where the person has not responded to other types of treatment [234]. Systematic review of 32 studies indicated that neurostimulation has shown promise for AN and BED, although results for BN are mixed [233]. DBS may present a unique opportunity for people with treatment resistant severe and enduring AN, however, due to its invasive nature it is difficult to find studies assessing this treatment with large sample sizes, with a large proportion being conducted as case studies or series [235].

Outcomes

Relapse is a significant issue experienced by individuals with eating disorder, with high rates observed among people with AN and BN, however, exact reported rates are highly variable due to differing definitions of relapse and remission used by researchers [236]. In one study, 41% of individuals with AN had relapsed by the 12-month follow-up [237]. AN-Binge Purge subtype was associated with a two-fold greater risk of relapse in this study sample, compared to AN-Restricting subtype [237]. Comorbid depression has also been shown to be a predictor of relapse [236].

There is emerging evidence that technology can be used to aid in the delivery of after-care and recovery monitoring programs. Mentoring programs may provide benefit in reinforcing recovery and is a potential area for future research. Relapse prevention programs trialed include internet-based programs, text-messaging programs and aftercare programs following inpatient admission. These have shown improvements of up to 50% remission at follow up [238] compared with treatment as usual, however, further research is required.

AN and BN are associated with the least favourable long-term outcomes of the diagnostic groups, and significant mortality risk. People with restrictive type eating disorders have the poorest prognosis. Up to 15-20% of individuals with AN will die from the illness [239] [240]. Adolescent presentations of AN are significantly less persistent and are associated with much lower mortality rates than adult presentations [241] [242]. People who experience binge/purge type eating disorders have the highest risk of relapse [243].

Compared with AN and BN, long-term outcomes and treatment success for people with BED are more favourable [244] [245], with demonstrated efficacy of available psychotherapeutic and behavioural intervention [244]. A diagnosis of EDNOS or OSFED is also associated with more positive outcomes.

Overseas studies have shown lower BMI, poor social adjustment, older age and longer duration of illness at service presentation in people with AN is associated with increased mortality risk [246] [242].

There have been no longitudinal studies investigating mortality in eating disorders in Australia.

Prioritising evidence uncertainties for research

Once gaps in evidence have been identified, it is essential to consider how they should be addressed and prioritised. Better connecting research with people's experience and including a range of stakeholders in setting research priorities, particularly people with lived experience, is essential.

> "Hearing from families and carers is so critical to understanding where the gaps in early intervention, treatment and relapse prevention are. Hearing from the coalface provides robust intelligence of where research needs to focus its attention and how it can be best treated."
>
> Belinda Caldwell, CEO Eating Disorders Victoria

Asking people who are impacted by eating disorders to identify issues that are of direct relevance and potential benefit to them, their families/carers, and the healthcare professionals who work with them, helps identify what research will make the most impact on the health and wellbeing of the community. A prioritisation process can then inform the clinical, research and policy sectors, and assist researchers (and the bodies that fund them) to make their research as practical and applicable as possible.

Evidence uncertainties and the priorities of the community change over time - as new evidence is introduced, old priorities are addressed by researchers, and the service and community landscape changes. As such, it is important that identification of evidence uncertainties and prioritisation of research is an ongoing process carried out as frequently as required, and at least every 3-5 years.

The current research and translation priorities

In 2020 a priority setting process was conducted using an internationally acknowledged method, the James Lind Alliance (JLA) method, to identify Australia's current Top 10 eating disorder research and translation priorities. (Read more about the method in Section 3 Strategy Development).

The JLA method generates a list of important areas for research that people whose lives are impacted by a particular illness feel need to be answered. If these evidence uncertainties were answered, they would help transform the lives and experience of people experiencing an eating disorder and their families.

The JLA priority setting process is flexible and responsive to the needs and contexts of different groups, while maintaining the following integral principles:

- Equal involvement of consumer, carer and clinician interests and perspectives
- Inclusivity and diversity of representation
- Transparency of process, methods and interests
- A commitment to using and contributing to the evidence base (priority setting only commences after the uncertainties have been formally verified as unanswered).

The Top 10 research and translation priorities are not technical research questions - it is the role of researchers and the research community to translate them into research questions that will generate knowledge and address evidence uncertainties.

More information about the JLA process and current evidence uncertainties is available [247] and can be accessed through the InsideOut Institute website (www.insideout.org.au).

Research resources and enablers

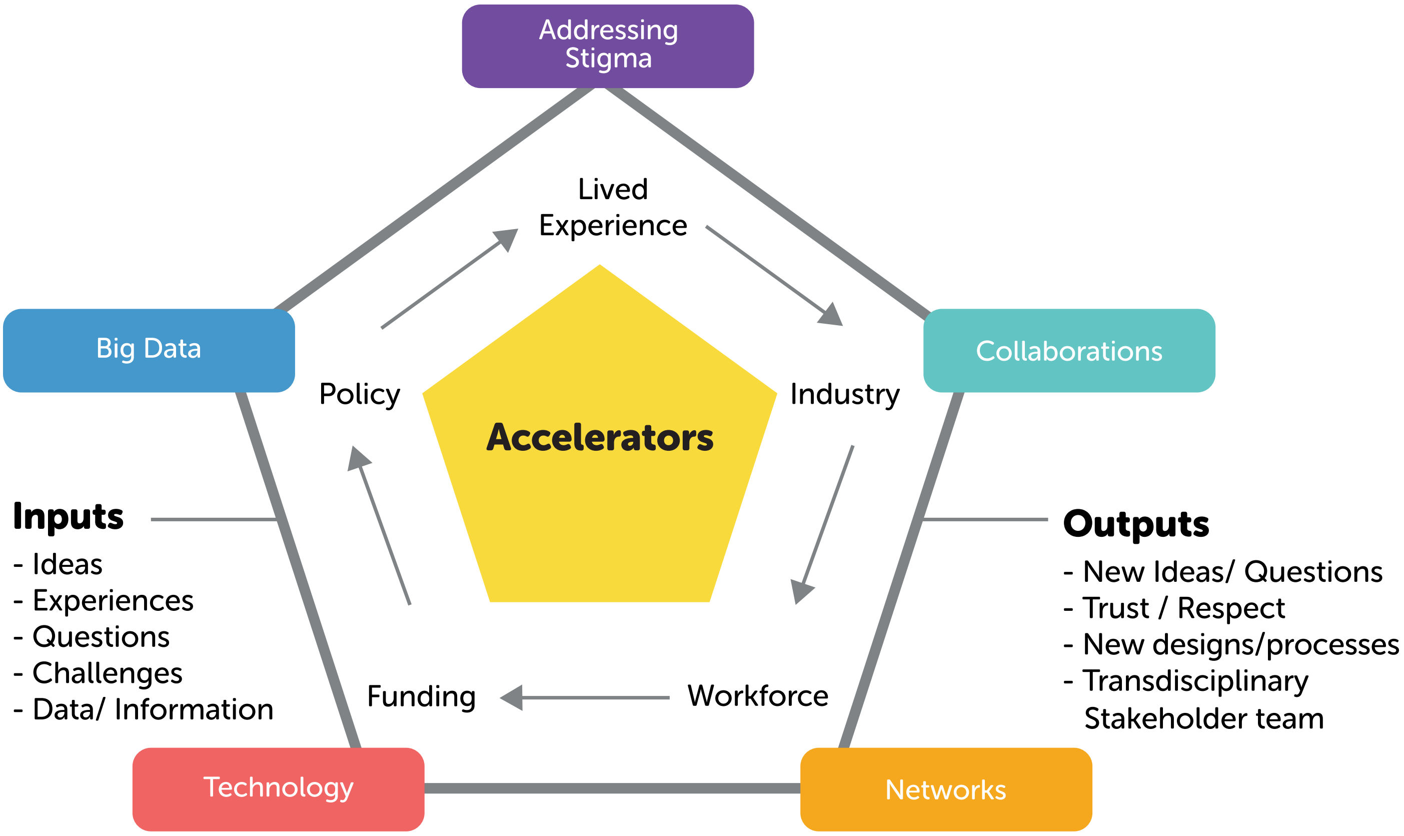
A wide range of research resources exist across Australia, including many research accelerators and enablers (diagram 6 below). Increasing visibility and accessibility of these valuable resources will enable investment into research to be maximised, increasing research outputs and impact.

To do this, supportive policy and adequate funding will be required. Harnessing the energy and commitment of people with a lived experience, ensuring a well-developed research workforce, and collaborating with government, industry and philanthropy to create novel partnerships will be essential. Some of the broader mechanisms and research enablers will also need to be targeted.

A strong and vibrant mental health research workforce is vital to delivering the evidence that enables the improvement of the mental health system to achieve better outcomes.

Many Australian eating disorder researcher roles include teaching and other research work relating to their discipline more broadly. Leadership roles (such as academic Chair(s) of Eating Disorder Research, which do not currently exist), funded positions in eating disorder research, as well as funded specialist services where clinical researchers work and develop expertise, would enable growth of the eating disorder researcher workforce. It is also essential to consider the mechanisms that will enable the growth of the clinical and lived experience researcher workforces.

Diagram 6: Research accelerators



Source: Adapted Horowitz et al 2017 [248]

Addressing stigma

On multiple levels, addressing stigma as a barrier is an important accelerator of research impact and outputs.

At the individual level, stigma and stigmatising views about mental illness are known to impact on treatment seeking (or disclosing illness), exclusion and isolation, and have adverse impacts on personal relationships, social interactions, employment, education and community involvement [249]. For people with eating disorders, stigma has been found to be a barrier to accessing help and recovery – impacting on psychological wellbeing, social and physical health outcomes, the likelihood of help-seeking [250] and eating disorder psychopathology [74].

At the practitioner level, stigma and stereotyping can impede identification of who is at risk or displaying symptoms of an eating disorder, as well as intervention and treatment – increasing the likelihood that eating disorders will be under-detected, under-diagnosed and remain untreated – impacting on people's long term health, morbidity and mortality.

Stigma also has systemic impacts on research and research funding. Research bodies and like institutions often undervalue the significant burden of eating disorders and as a result eating disorder research remains very under-funded. In addition, research agencies and funding reviewers are also community members and subject to the same influences of stigma as others in the community. For example, research indicates that people with eating disorders, more than other mental illnesses, are considered responsible for their own illness [251] [252]. To accelerate eating disorder research and translation, it is important to ensure that stigma plays no role in the allocation of research dollars and that investment is driven by burden and impact on people's health and wellbeing.

Networks and collaborations

Networks and collaborations addressing eating disorder research do exist in Australia, however, they are frequently informal and ad hoc. The Victorian Eating Disorders Research Network (VEDRN) has been established by a group of interested academics, researchers, clinicians and advocates working in eating disorders research, to strengthen the practice of research in Victoria and support better outcomes for people with eating disorders and their families. Facilitating and supporting the development of similar networks across jurisdictions is an important role for state-based eating disorder organisations and interest groups.

Clinical trials networks are large collaborations (i.e. national or state-based and extending into regional and remote areas) between clinician researchers from all disciplines who design large multi-centre clinical trials to answer important clinical questions. This may occur in partnership with industry stakeholders. The broad distribution of a clinical trial network means that trials conducted are likely to be representative of practice in the real-world, and they provide opportunity for training and mentoring [253].

Growing local, state and national networks will help facilitate and enable high quality research that has maximum impact.

Technology

Digital technologies are a key enabler for ensuring high quality research and its translation into practice. New and existing technologies can be utilised to ensure data capture as part of routine practice, improve access to research networks and researchers, expand data collection and data sources, generate opportunities to provide and test treatments that can be delivered through digital technologies in real-world settings – expanding access to specialist, evidence-based treatment regardless of where a person lives. Access to workforce development and training opportunities can be provided through digital technologies.

Data

Including eating disorders in all national mental health and health data collection opportunities will provide a clearer national picture of the impact of eating disorders on the Australian community. Important Australian health data collection opportunities have historically neglected eating disorders. For example, the Deloitte Access Economics report (2012) recommended inclusion of eating disorder questions in the Australian National Mental Health Survey, a call which was re-iterated in 2018 by Australian researchers Hart and Wade who also note that the 2013-2014 national Child and Adolescent Survey of Mental Health and Wellbeing did not include eating disorders [85]. The upcoming survey will, for the first time, include a question relating to eating disorders.

Data sharing, establishing data networks and linkage of data sources are also essential to accelerating understanding of morbidity and mortality, impact of illness and treatments, and wellbeing and outcome over time. There are great opportunities to answer pressing research questions in the field of eating disorders through access to existing big (and smaller) data systems, and these need to be prioritised for funding and access.

3

Strategy Development

A dynamic co-production

Release The National Eating Disorder Research & Translation Strategy, including the identification of the Top 10 research and translation priorities has been co-designed including a robust, extensive national consultation process conducted 2019-2020.

As the project lead, the InsideOut Institute for Eating Disorder Research worked in collaboration with an Advisory Committee including eating disorder expert researchers, clinicians, people with a lived experience, as well as jurisdictional representatives and research and translation experts from the broader mental health community. The Advisory Committee oversaw the process and contributed to the development of the Strategy. A National Eating Disorder Research Collaboration and a Lived Experience Research Advisory Group also contributed to the development and review of the document. Department of Health representatives from federal, state and territory governments, as well as clinicians, researchers, academics, people with a lived experience (consumers and carers), eating disorder organisations, services, practitioners and translation experts, provided a range of perspectives at key consultation points.

Consultation Phase 1

Nation-wide consultations were conducted in each state and territory – with coordination support from state and territory eating disorder organizations. Consultations with more than 480 individuals, representing 80 organisations, 10 peak bodies and 40 expert researchers were collaborative and cross-sectorial, attended by consumer and carers, clinicians and service providers, public and private providers, academics and researchers, and representatives from state and national mental health commissions. Department of Health representatives from federal, state and territory governments were represented at each consultation.

Consultation participants identified gaps and developed priorities across three domains – research, translation and the implementation of evidence.

Consultation Phase 2

A series of specific lived experienced focused consultations were conducted - promoted through consumer and carer organisations with broad geographical participation achieved through an online consultation processes.

Key carer and consumer groups were involved in coordinating and promoting the Phase 2 consumer and carer consultations.

> “Our voice provides insight and a perspective that cannot be obtained from data alone.”
>
> Shannon Calvert, Lived Experience Educator

Consultation Phase 3

The draft framework for this document was distributed for comment to the over 400 individuals who participated in early phases of consultation. It was also sent to the following professional organisations for review and feedback:

- The Royal Australian College of General Practitioners
- The Royal Australian and New Zealand College of Psychiatrists
- The Australian Psychological Society
- The Australian College of Mental Health Nurses
- The Australian Primary Care Nurses Association
- The Dietitians Association of Australia
- The Australian Association of Social Workers
- The National Mental Health Consumer & Carer Forum
- Mental Health Australia
- Sane Australia
- The Butterfly Foundation

All feedback from phase 3 consultations was integrated into the document.

Consultation Phase 4

The final consultation occurred across two stages:

Stage 1: Top 10 Research & Translation Priorities for Australia

As briefly outlined above, an independent process was conducted to identify the Top 10 research and translation priorities for Australia. The James Lind Alliance-aligned priority setting process included:

- Engaging a consultant from the James Lind Alliance in the UK to undertake the process.
- Establishing a representative advisory committee, including a consumer, carer, clinician and researcher representative. The role of the Co-Design Advisory Committee was to monitor the process, provide plain language recommendations, participate in developing each element of the process and observe the workshop. From there,
- 1210 issues, identified during national consultations for the development of the Strategy, were developed into plain language questions – or, areas of evidence uncertainty that, if answered by research, would transform people's lives and the health care journey.
- These questions were coded into topic areas, they were categorised, merged, summarised and checked against existing research evidence to ensure that they had not already been answered by the existing knowledge base.
- 59 Questions were then taken to a national online survey, approved by the Sydney Local Health District.

Human Research & Ethics Committee, which established an interim priority list. 160 consumers, 79 carers, 140 clinicians and 52 researchers responded to the survey, selecting their own ‘Top 10’.

- The JLA consultant reviewed the survey responses and the top 16 questions were reviewed during a 2x workshop series, where equal numbers of consumers, carers, clinicians and researchers came to a consensus around the current priority areas for research and translation.
- The ‘Top 10’ were then ‘translated’ by researchers and the research community into technical research questions.

The infographic below broadly demonstrates the Priority Setting research process.

ED Top 10 Priority Setting Partnership

Gathering Questions About Eating Disorders

National Consultations identified 1210 Questions

480+ individuals
80 organisations
10 peak bodies
40+ eating disorder researchers
Lived Experience Research Advisory Group

Establishing a JLA Co-Design Advisory Committee

Consumer

Clinician

James Lind Alliance Independent Chair

Researcher

Carer

Working With the Data

1210 Questions Coded into Topic Areas

1. Prevention
2. Origin of eating disorders
3. Social & emotional determinants
4. Early identification
5. Treatment
6. Diagnosis
7. Data
8. Epidemiology
9. Recovery
10. Research
11. Translation
12. Workforce
13. Communication

Questions categorised, merged, summarised & checked against existing research evidence into 59 Questions

Interim Priority Setting: A National Survey

160 Consumers

140 Clinicians

431 individuals chose their Top 10
The top 16 questions taken to consensus workshops

52 Researchers

79 Carers

Consensus Workshops

JLA facilitators conducted Zoom Workshops with equal numbers of consumers, carers, clinicians and researchers

JLA methodology used to reach consensus about the Top 10

Stage 2: Final Consultations

The final draft of the Strategy was reviewed by the Australian Eating Disorder Research Collaboration and a Lived Experience Research Advisory Group, as well as individual consultations with jurisdictional (state and territory) representatives, national eating disorder organisations and state/territory eating disorder NGOs and service providers. The Strategy was also distributed to the National Mental Health Commission for comment, prior to being submitted to government.

4

Strategic Priorities and Recommended Actions

Strategic Priority 1:

Support and generate a culture of research and translation excellence

A culture that is supportive of research and translation excellence includes strong, effective leadership – from individuals, teams, across government and relevant organisations. It values the generation of meaningful research that impacts people's lives, so its policies, systems and structures are directed to this objective. Embedded within such a culture is a person-centred recovery focused and trauma informed approach – whereby the lived experience voice is central and research spaces are culturally aware and safe for all.

Australian researchers, including clinician and lived experience researchers, have made a significant contribution to the global knowledge base. To date, this work has not been well supported (either financially or systemically) both of which are required - committed and passionate individuals cannot drive the eating disorder research and translation agenda alone.

We want to build on our strong track record in research excellence to develop a research ecosystem that delivers an inspirational and innovative research agenda, attracts great researchers, innovators and disruptors, delivers research that improves people's lives, and values a range of research approaches, methodologies and perspectives.

A thriving research ecosystem needs leaders who are well supported and will require structural changes to the way research investment and planning occurs, and a coherent vision for excellence that is clearly articulated and communicated broadly. This will require broad action across the system - effort across sectors as well as collaboration between organisations and individuals. Collaboration and partnerships between researchers (and academic institutions), community, clinicians (and service providers) and people with a lived experience (consumers/carers) in the planning, resourcing and conduct of research, as well as within the systems and processes that support high quality research and translation (such as networks), are essential.

Priority reforms and specific actions that will support and generate a culture of research and translation excellence are outlined below.

Leadership

Develop structures that ensure eating disorder research & translation leadership at all levels - individuals, teams, organisations, systems.

Actions that would help achieve reform:

1. Create permanent Professorial Chairs of Eating Disorders at leading academic institutions as foundations for building research hubs.
2. Establish Research Centres of Excellence to drive the research and translation agenda forward, support research teams to develop the skillsets required to apply for grant funding and increase competitiveness of eating disorder research funding applications.
3. Foster an environment of cooperation and support to enhance collaboration.

4. Foster the creation of culturally aware and safe spaces to conduct research.
5. Establish mechanisms that connect research leaders with researchers across Australia, from metropolitan, regional, remote and very remote areas.
6. Promote and support lived experience research leadership.
7. Promote and support clinical research leadership.
8. Promote the value of translation and prioritise translational research within the research sector – for example, research leaders promote research translation as a key professional activity.
9. Use change management strategies where necessary to engender a culture that values research, is invested in its success, and is willing to adapt research evidence into practice.
10. Encourage a research and quality assurance culture in everything we do for the prevention and treatment of eating disorders.
11. Support the conduct of meaningful and impactful research.

Collaboration

Collaborate to support a thriving research ecosystem that attracts the best and brightest.

Actions that would help achieve reform:

1. Establish an alliance of funders, researchers, policy makers, service providers and those with lived experience.
2. Establish partnerships between academic centres, clinical services and experts by lived experience, to create natural research hubs, linked to health service pathways and community.
3. Establish shared investment approaches, where resourcing for research and translation projects can come from multiple sources (e.g. individuals, services, government, philanthropy and industry).
4. Establish collaborations across sectors, between organisations, services and disciplines, including innovators from other fields, sectors and environments.
5. Establish collaborations with clinicians and clinical researchers, educators and education researchers, and professionals and researchers from relevant fields and sectors.
6. Build and support international research and translation collaborations, led by research sites in Australia, including, for example:
    - creating international fellowship exchange opportunities to expand context for knowledge exchange and to attract leading national and international academics to visit research sites in Australia, and
    - collaborating with international colleagues on Australian-based research projects.
7. Establish knowledge exchange/scholarships for early career researchers to spend time in laboratories around Australia or overseas, to develop skills and networking collaborations with global leaders.
8. Establish research communities of practice.

9. Support dynamic local (state and territory based) research networks, including regional, remote and very remote areas, to establish collaborations across common areas of interest.
10. Encourage research organisations to develop position statements that articulate the principle of co-design – including with clinicians and people with a lived experience (consumers and families/carers).
11. Establish lived experience editorial positions within journal editorial boards.
12. Identify opportunities to support the work of colleagues, promote research output to build strong track records in the field (e.g., cite important research from the field, strategic assignment of chief and associate investigator roles to develop careers, and be supportive of quality work when reviewing).

Communication

Clear and regular communication about research, support for research and the outcomes and impact of research.

Actions that would help achieve reform:

1. Develop a national communication strategy about eating disorder research and translation, to build community understanding and engagement with research and its impacts.
2. Ensure eating disorders are included in all national mental health stigma reduction campaigns/strategies.
3. Develop communication strategies to inform the workforce/sector about all available research opportunities (e.g., projects, funding, partnerships, collaboration).
4. Communicate the value of research; to enhance the research culture within clinical organisations, and to support clinicians to value evidence-based practice.
5. Develop strategies to support clinicians and people with a lived experience to build confidence to be involved in the research process.
6. Include lived experience perspectives, and support lived experience involvement, in all stages of the research process.
7. Elevate the profile of eating disorder research evidence in the media.
8. Promote the importance of eating disorder research and knowledge translation to generate a supportive ecosystem.

Strategic Priority 2:

Generate high quality research that impacts health outcomes and improves wellbeing

To enable and enhance, meaningful, high-quality research it must be adequately funded. Investment in research is everyone's business: research and the knowledge generation from it happens at all places in the system. A range of funding models is required, and all types of research need enhanced funding support. Investment from multiple/varied sources including government, philanthropy and novel sources, allocated commensurate with illness burden, morbidity and mortality, will make a perceptible difference.

We know that knowledge and translation gaps exist across all areas of inquiry, including:

- Basic science (the factors and mechanisms involved in the cause and maintenance of eating disorders)
- Population prevalence, disease burden and quality of life
- Risk factors, screening and prevention
- Diagnosis and early intervention
- Treatment and models of care
- Recovery, relapse prevention and outcome.

Addressing knowledge gaps means ensuring that eating disorders are identified as a national research priority and integrated through all national health and mental health research mechanisms and bodies, as well as in all national mental health policy and projects. Systems that support the conduct of high-quality research across a range of areas - from establishing networks for researchers to collaborate at local and national levels, through to digital innovation and data collection – need to be established. Research into the organisational systems and structures that deliver eating disorder interventions and treatments would help to highlight opportunities for improvement.

Funding from all sources needs to support innovative ideas and the agreed priorities that researchers, clinicians, consumers and families recommend (visit the InsideOut Institute website for the current Australian research and translation priorities, established through a collaborative priority setting process).

As a community, we want to prioritise research and translation design practices that change the way we do things. This means ensuring research is co-designed, co-produced and co-delivered, so that it addresses knowledge gaps, is innovative, agile and cost effective. Prioritising the lived experience voice means better understanding the experience of eating disorders on all those who are impacted by them, including Aboriginal and Torres Strait Islanders, people from diverse backgrounds and people who don't meet the commonly accepted stereotypes, people of all cultures, ages, gender identities and body shapes, as well as their families and supports. We want to ensure that research informs how people and their families can be better supported and empowered, particularly across transition periods, which we know is a risk period and a time when some slip through the cracks. Research focused on individualised approaches to treatment will help to improve the health care journey.

Quality improvement projects, evaluation of services and programs, pilot studies, consumer satisfaction surveys, program outcome measures, pre- and post-symptom measures – these are all research activities with the opportunity to impact the knowledge base, if properly funded and the output data is collected, analysed and utilised in meaningful ways. It is also essential that public funds are only invested in broad-scale interventions (across the spectrum from prevention to treatment) where an evidence-base has been firmly established.

Priority reforms and specific actions that will generate high quality research that impacts health outcomes and improves wellbeing are outlined below.

Funding

Grow the funding base to enable highest quality research.

Actions that would help achieve reform

1. Add eating disorders research to core funding for all mental health schemes.
2. Establish targeted calls for eating disorder research from national funding bodies such as the National Health & Medical Research Council, Australian Research Council, Million Minds Research Fund.
3. Establish the structures to support competitive application for Research Centres of Excellence.
4. Encourage and provide incentives for shared investment in research funders from across different sectors (public, private, academic, commercial, and philanthropic) to coordinate their efforts and ensure effective use of resources.
5. Provide incentives for corporations and individuals to donate funds for eating disorder research.
6. Increase flexibility in funding criterion for charities and NGOs, to encourage and enable innovation and high-quality evaluation.
7. Develop a fundraising strategy to encourage research funding from novel sources - e.g., private companies, philanthropy, free treatment options.
8. Ensure that service provision funding is for evidence-based treatment and that this is evaluated and demonstrated.
9. Ensure project funding includes allocation for high quality evaluation.

Priority driven research

Prioritise research and translation activities that address urgent knowledge gaps and maximise impact.

Actions that would help achieve reform:

1. Conduct an iterative consensus-based priority setting process with equal input from consumers, carers, clinicians and researchers, to be updated as required.
2. Establish targeted calls for research based on consensus priorities by government and funding agencies.
3. Establish an online repository of research opportunities that reflects consensus-based priorities, and which can be drawn on by students and researchers.
4. Support new and innovative research - basic, applied and translational – ensuring that Aboriginal and Torres Strait Islanders, those from diverse and vulnerable populations, as well as families and supports are included.

Networks

Establish research networks with defined purpose to support the conduct of high-quality research and its translation.

Actions that would help achieve reform:

1. Ensure researcher networks that are effective and inclusive of all types of researchers at all stages of their career and are accessible across all geographical areas.
2. Establish a National Eating Disorder Research Network.
3. Establish a National Eating Disorder Research Trial Network.
4. Collaborate with the Australian Clinical Trials Alliance (ACTA) to establish a National Eating Disorder Clinical Trials Network.
5. Establish a National Eating Disorder Lived Experience Research Network.

Data

Collect data on everything we do.

Actions that would help achieve reform:

1. Develop agreed valid and reliable measures of treatment quality, health outcomes and economic impact - e.g., a National Minimum Clinical Data Set for eating disorders.
2. Incorporate eating disorder relevant markers into all routine health and mental health data sets collected nationally and across states and territories. E.g.,
    - Establish research tools to capture data at ‘point of care’ that are not onerous, and
    - Require all practitioners providing treatment through the Eating Disorder Medicare funding mechanisms to collect data about core elements of treatment.
3. Establish standardised evidence-based treatment and outcome monitoring in all health services providing treatment to people with eating disorders and other high-risk groups.
    - Develop tools and supports that maximise readily accessible high-quality data sources, e.g.,
    - Establish a national universal data collection hub linked to other data (e.g., health department) and mechanisms (e.g., MBS Eating Disorder Item Numbers),
    - Establish a National Registry for people with Eating Disorders, and
    - Make existing datasets more widely available and foster data sharing.

Strategic Priority 3:

Grow the research workforce capacity and capability

For research to occur, a well-supported research workforce is essential. We want to develop the research workforce capacity and capability and foster a talent pipeline of outstanding Australian researchers - including academic researchers, clinical researchers and lived experience researchers – from post-graduate researchers through to early career researchers and senior research fellows.

To do this, we need to identify and attract high quality students to higher research degrees by establishing scholarships and creating opportunities for them to integrate work and learning opportunities. They need to be mentored and supported to build their knowledge and skills across all research methodologies and in collaboration with people who have a lived experience, carers/families, and clinicians. Supportive policies and guidelines need to be established across relevant sectors including sport, education, and health.

We also need to look to the existing workforce – particularly those working clinically in eating disorders services and primary care - as well as people with a lived experience who are ready to share their knowledge and expertise but aren't sure how. With the right training and support, clinicians and people with a lived experience engage with research, better utilise evidence in their practice, collaborate with data collection, and support and value research application in real world settings.

Embedding researchers in real world settings, where people develop eating disorders and are identified and treated, requires concerted effort regarding workforce development. Innovative and collaborative research workforce development programs need to be established – for example, Researcher Hot House Programs where a talented and diverse cohort of graduates and post-doctoral researchers work together with people with a lived experience, seasoned academics and expert and novice clinicians to pursue fundamental questions and translate ideas and research into action.

Priority reforms and specific actions that will grow the research workforce capacity and capability are outlined below.

Capacity Building

Grow the research workforce from post-graduate through to early career researcher and senior research fellows, including lived experience and clinical researchers.

Actions that would help achieve reform:

1. Attract high quality students with scholarships, develop them with training and mentorship to transition them to early career researcher.
2. Establish clinician researcher scholarships for higher research degrees and fellowships, to grow the clinical research workforce.
3. Provide lived experience researcher scholarships for higher research degrees and fellowships, to grow the lived experience researcher workforce – including in NGOs, Aboriginal health services and community organisation settings.
4. Fund and facilitate clinician and lived experience time for research participation.
5. Establish and support programs (e.g., mentorship, internship) for the development of early career researchers in research centres.
6. Establish clinical research internships, where maintenance/fidelity strategies like supervision and support are provided.

Education and development

Improve education, training, and support for the research workforce, including lived experience and clinical researchers.

Actions that would help achieve reform:

1. Collaborate with university leaders to embed learning activities promoting eating disorder research and translation into all undergraduate and postgraduate health professional degrees.
2. Develop postgraduate training in eating disorder research skills for multiple disciplines including grant writing development, methodology training, publication writing, planning career enhancing experiences.
3. Train the existing workforce (clinical and lived experience) in research and evaluation methods.
4. Ensure grants and scholarships for post-doctoral researchers, early career researchers and clinical fellowships, provide sufficient funded time for reflection and supervision.
5. Ensure maintenance/fidelity strategies like supervision and support are provided to existing clinicians in clinical and treatment settings.
6. Provide opportunities for peer mentoring across community (e.g., NGO) clinical and research networks.
7. Collaborate with professional associations that provide training and continuing professional development to their members.

Policy

Ensure strategies & policies develop the research workforce, including lived experience and clinical researchers, across relevant sectors.

Actions that would help achieve reform:

1. Develop an implementation plan for this Strategy including development of the eating disorder research and translation workforce.
2. Establish a Scope of Practice document that identifies agreed knowledge and skills for post-doctoral eating disorder researchers - ensuring sufficient guidance and structure is provided, as well as enabling flexibility and inclusivity.
3. Embed policies and strategies that address barriers to translation and implementation of evidence in health services and by clinicians.

Embed researchers

Embed research into the existing workforce in all relevant areas.

Actions that would help achieve reform:

1. Establish research positions in settings where eating disorders develop, are identified and treated (e.g., schools, primary care including general practice).
2. Embed research coordinators into existing eating disorder treatment centres/service providers, networked with each other and the lived experience research workforce.
3. Establish research positions within community-based eating disorder peak bodies, Aboriginal health services and NGOs – this requires funding and cultural support and commitment to the value of research and translation.
4. Establish models where post-doctoral researchers are linked to community and clinical centres.
5. Identify research champions within community and clinical services who can support clinical research.

Strategic Priority 4:

Accelerate the impact of research

Translation of knowledge from laboratories into real-world settings must occur to accelerate the pace, scale, and impact of innovation, culminating in research that works. Improving research capacity and ensuring that knowledge translation occurs is also a social justice issue because it supports increased equity of access to evidence-based programs, interventions and treatments by transforming service delivery for all people, at all levels.

The focus of this strategic priority is to support the development of integrated clinical and research pathways for best practice across the prevention-treatment spectrum. It is also essential that there are sufficient eating disorder treatment services in every state and territory that embed research and translation in practice – this is a significant gap in the current service landscape and needs to be addressed as part of a broader approach to an eating disorder strategy nationally.

It is widely acknowledged across all areas of research that the timeframe from evidence generation to the use of evidence in practice needs to occur more rapidly than it currently does. Improving the speed of knowledge translation requires that we:

- conduct and apply research in real-world settings (co-location) and at point of care, making sure that it is relevant and able to be applied in a meaningful way – practice and lived experience wisdom can transform research.
- prioritise translation of evidence-based interventions that are fit-for-environment, accessible, cost effective, and acceptable to the users (consumers, carers, those delivering interventions) and environments in which eating disorders are developing; and
- develop mechanisms to ensure that research evidence is used to inform and transform practice in all settings – facilitating practice change.

For prevention and health promotion for example, this may mean conducting research in settings such as schools, universities and other relevant organisations, communities, and sectors. For research that improves early identification and first point of contact experience, this would mean prioritising research that occurs in, and supports those in, general practice, headspace centres and other primary care settings.

Translational activities need to be evidenced based, and as such, occur after evidence of efficacy has been established. However, the translational elements of research still need to be considered during the research design process, and translational research must be conducted based on high-quality frameworks that are designed to address barriers and impact policy and practice.

Priority reforms and specific actions that will accelerate the impacts of eating disorder research are outlined below.

Funding

Fund research in real world settings.

Actions that would help achieve reform:

1. Include dedicated research/evaluation allocation in the funding matrix of all clinical eating disorder services (e.g., public, private, NGO, community).
2. Share funding of research across sectors, organisations and services – building equal partnerships between the healthcare community, service providers, NGOs, Aboriginal health services, education providers, as well as the broader general community, alongside academia.
3. Invest in quality improvement and evaluation to systematically improve practice.

Policy

Establish policies and practice that support data collection in real world settings and accelerate the impact of research.

Actions that would help achieve reform:

1. Work with relevant governments and organisations - e.g., the Centre for Informing Policy in Health with Evidence from Research (CIPHER) to ensure that eating disorder translational research is conducted and used to inform public policy.
2. Develop National Practice Standards for Eating Disorders that include standardised tools and documentation, including tools that have been validated for use with Aboriginal and Torres Strait Islanders, as well as people from diverse and vulnerable populations.
3. Address barriers to culture change within clinical services and other settings.
4. Support policy makers to incorporate evidence into policy and strategy, through the provision and promotion of evidence reviews and summaries.

Practice

Conduct translational research based on high-quality frameworks and address barriers to shorten the timeframe from evidence generation to adoption in practice.

Actions that would help achieve reform:

1. Ensure translation is considered and included in research proposals.
2. Plan for rapid translation in the earliest part of the research design phase, aiming to generate evidence relevant for policy and practice uptake.
3. Invest in research that explores eating disorder systems and models of care.

4. Conduct research that utilises high quality translational frameworks e.g., RE-AIM, Knowledge-to-Action, PARiHS.
5. Anticipate likely barriers at the intervention, individual, organisational and government levels, and provide mitigation strategies to increase the speed at which interventions reach end users.
6. Identify likely barriers at key research junctures, including: the characteristics of the intervention, characteristics of the setting and characteristics of the research design - and establish mitigation strategies to address these.
7. Apply simulation modelling methods to examine potential effects of policy changes, multiple exposures, and moderators under varied conditions.

Co-location

Build research capacity within existing clinical/treatment hubs and relevant community areas.

Actions that would help achieve reform:

1. Conduct research in the setting it will be delivered - schools (primary/secondary), primary care, general practice, headspace, Aboriginal health services, the community and other relevant settings.
2. Co-locate research, community (including peak bodies and NGOs) and clinical services to help innovate treatment and close translation gaps.
3. Support the existing health workforce to use evidence in practice and collect data as part of practice - in specialist and non-specialist settings.

Communication

Improve the way research and its translation is communicated.

Actions that would help achieve reform:

1. Engagement between researchers, policy makers, practitioners and the community to develop and broaden opportunities for communicating the outputs of translational research, extending research results beyond academia, e.g.:
    - Use plain language when communicating evidence
    - Support researchers to develop knowledge-translation communication skills
    - Support researchers to understand and promote evidence-informed decision making (EIDM) in ways that decision makers (e.g., funders, policy makers, service leaders) understand, and
    - Work with journalists to cultivate relationships around sharing and communicating knowledge and research findings.
2. Identify and eliminate barriers to translation through a targeted communication approach – disseminating research findings and innovations across health and other relevant sectors.

3. Increase knowledge and understanding of the value of research and how to be involved - e.g.,
    - Ensure inclusion and feedback to all contributors to research and translation activities (including consumers, carers and clinicians) is accessible and culturally appropriate.
4. Work with eating disorder Journals to increase support for eating disorder research and translation dissemination.
5. Make funding available to publish in open access journals so that data is easily accessible.
6. Present outside of the field including at eating disorder and broader health and mental health events - e.g., education, sport, nutrition and general health and mental health events, publications, editorials.
7. Use ambassadors and influencers to promote best practice – raising the general awareness of what constitutes evidence-based practice to increase the demand for evidence-based services.

Strategic Priority 5:

Broad implementation of evidence-based practice and practice informing evidence

Increasing and sustaining the use of evidence in practice across the system and by all participants within the system, is central to the challenge of addressing the devastating impact of eating disorders on the health and wellbeing of millions of Australians. This requires the integration of researchers into practice settings, the establishment of quality mechanisms for implementing evidence into all relevant areas of practice, and for audit and feedback from practice to help inform the evidence in an ongoing cycle.

Interventions need to fit within settings that impact the most on people's health and wellbeing. Rather than simply emphasising evidence-adoption, implementation models and programs need to be established that build on local knowledge and available community resources, strengthen capacity, and adapt to the local setting, context and need.

Providing effective, sustainable, and accessible evidence-based programs, treatments and services requires the support of implementation science. In addition, the existing workforce – across a range of relevant sectors, disciplines, and settings – needs to be supported to apply evidence to their work. They need access to evidence through easy-to-find sources and they need support to engage with effective workforce practices – such as professional development, audit and feedback, coaching, reflection and importantly, eating disorder focused clinical supervision. Staff allocated to facilitate these activities in a workplace, and support the cultural change required for it to occur, are required for implementation of evidence into practice.

The tables below identify priority reforms and specific actions that will support broad implementation of evidence-based practice and practice informing evidence.

Funding	**Provide funding and ongoing support for implementation science.**

Actions that would help achieve reform:

1. Identify research funding sources and develop collaborative funding mechanisms that support implementation of the best evidence.
2. Provide clear advice to government and other funding agencies around programs for national and broadscale roll-outs – whereby only interventions with the strongest available evidence base should be supported.
3. Develop the workforce across all relevant sectors, disciplines and services, e.g.,
   - Ensure sufficient staff are allocated to champion and undertake research implementation, evaluation and innovation in specialist eating disorder settings.
4. Establish innovative interactive approaches to support practice change and improve outcomes for the person, their family and supports.

Capacity building and training

Upskill the workforce in evidence-based interventions.

Actions that would help achieve reform:

1. Enhance capacity of the health sector to utilise evidence to address gaps in services.
2. Ensure organisational culture and attitudes are supportive of, and responsive to, the need to implement and utilise evidence-based interventions – at all levels, including policy makers, administrators, managers and individual practitioners.
3. Apply strategies such as change management and quality improvement, to support practice change wherever required.
4. Establish professional development programs around evidence-based health promotion and illness prevention, screening, identification and early intervention for a range of learner audiences and for those working with Aboriginal and Torres Strait Islander peoples, and those from diverse and vulnerable populations.
5. Link clinical services with existing providers of evidence-based professional development for clinicians and support fidelity to these approaches though clinical supervision.
6. Support clinicians to develop the skills of appraisal and integration of evidence; and evaluate the impact of ongoing professional development on the health outcomes and wellbeing of people with eating disorders, their families and supports.
7. Establish accountability structures (e.g., administration, peer networks) and/or incentive programs, used in combination with professional development, to support adherence and competence in evidence-based practice.
8. Establish and support communities of practice.

Access to knowledge

Develop health information systems that enable ready-access to evidence for frontline clinicians and people with a lived experience.

Actions that would help achieve reform:

1. Establish and promote readily accessible synthesised summaries of evidence.
2. Provide an open access resource repository for evidence–based pathways and protocols for all practitioners in all settings - including exemplar models of research translation (in any field) – that are relevant and accessible to all, including Aboriginal and Torres Strait Islanders and people from diverse and vulnerable populations.
3. Develop or enhance existing clinical decision-making tools and aids to prompt best practice at point of care - e.g., apps, digital tools.
4. Establish programs and platforms, to inform people with a lived experience (including consumers, families and carers) about the evidence and to inform researchers, clinicians and others about the lived experience.

Models and programs

Develop, implement, evaluate and sustain evidence-based models and programs.

Actions that would help achieve reform:

1. Ensure all specialist eating disorder services embed research and research evidence into practice through synthesis, dissemination and utilisation of the evidence. E.g.,
    - Undertake continuous quality improvement programs to improve evidence uptake.
    - Plan the design, implementation, adherence and evaluation of system-wide changes that facilitate practice that is evidence-based.
2. Research models that support intervention integrity (that is, consistent application of an evidence-based approach) and sustainability relevant to a range of settings – such as ongoing coaching, mentorship, clinical supervision and consultation.
3. Establish innovative evidence-based systems, models and programs that support multifaceted prompts/ reminders to utilise evidence-based interventions (e.g., for GPs, mental health clinicians).
4. Customise models and treatments to ensure they are relevant and culturally appropriate to Aboriginal and Torres Strait Islanders.
5. Customise models and treatments to ensure they are relevant and appropriate to people from diverse and vulnerable populations.
6. Develop and evaluate exemplar models of research and translation to demonstrate how it could work (e.g., how private clinics could link with universities).

Policy

Policy that supports evidence implementation.

Actions that would help achieve reform:

1. Ensure state/territory and national policies and strategies consider and addresses service and treatment gaps, in response to evidence, and bridge the nexus between research and practice.
2. Ensure public health policy is reflective of the diversity of people who experience eating disorders and those who care for them – including Aboriginal and Torres Strait Islander peoples, people from vulnerable populations, people of all ages, all cultural backgrounds, all genders and all types of disordered eating and eating disorder.
3. Ensure public health policy promotes messaging around eating disorder evidence and research, considering helpful and unhelpful messaging around body image, eating behaviours and weight, and is developed in collaboration with people with a lived experience and researchers.
4. Ensure the development of guidelines, policies and clinical practice standards are based on the best available evidence.

5 The Blueprint for Action

Who could do what…

The actions the eating disorder community have identified in the previous section are only some examples of what needs to happen to achieve the vision for eating disorder research and translation excellence in Australia. Everyone involved in eating disorder research, prevention, intervention and treatment has a role to play – as do the sectors and systems which support them.

Responsibilities across the system:

All contributors have a responsibility to:

- Identify and respond to key knowledge gaps required to improve the health and wellbeing of Australians with eating disorders.
- Implement evidence into all areas across the system.
- Ensure relevant areas across the system translate and take up research findings.
- Collaborate to change systems and practices.
- Value lived experience input.

In addition to the broad responsibilities, the following contributors have specific responsibilities:

Researchers:

- Undertake research that is of high quality, innovative and ethical.
- Undertake research that responds to the principles outlined in this document (see page 14).
- Undertake research of importance and is meaningful (solves real world problems).
- Partner with people with a lived experience, clinicians, communities and relevant others in undertaking research that contributes to the knowledge base and addresses knowledge gaps.
- Ensure the diversity of lived experience voice is reflected in research and translation priority setting processes.
- Share information and data wherever possible.
- Develop communication skills to share research findings.

Universities and other organisations that perform research:

- Continue to attract and support high-performing researchers.

- Collaborate with health services and other organisations in the provision of facilities and support services that foster research, translation and implementation of knowledge.
- Establish strategic partnerships with relevant organisations, institutes and funding bodies.
- Encourage collaboration across jurisdictions, internationally, across disciplines, schools and sectors.
- Support the growth and development of the research workforce.
- Share data, information and knowledge where possible.

InsideOut Institute for Eating Disorders Research:

- Promote and progress the Australian Eating Disorder Research and Translation Strategy – with government, with industry, with philanthropy, with research organisations, health services and community.
- Advocate for eating disorder research to be funded proportionate to disease burden.
- Advocate for eating disorders to be included in all relevant national mental health data collection.
- Advocate for policy change, bringing researchers, clinicians and community together.
- Support the growth and development of the research workforce including clinician and lived experience researchers.
- Support and promote research and translation with Aboriginal and Torres Strait Islander peoples.
- Support and promote research and translation with people from diverse and vulnerable populations.
- Support the communication, translation and implementation of research evidence into practice in all settings.
- Advocate for effective pathways for knowledge translation and implementation.
- Showcase research through events and training delivered.
- Establish innovative partnerships and commit to co-design and co-production in all stages of the research process.
- Collaborate with researchers, universities, research organisations, national peak bodies, health and social sector, eating disorder community organisations, professional organisations and others, to advance eating disorder research and translation in Australia.

Eating Disorder National Peak Bodies:

- Promote and progress the Australian Eating Disorder Research Strategy – with government, with industry, with philanthropy, with research organisations, health services and community.
- Advocate for eating disorder research to be appropriately funded.
- Advocate for eating disorders to be included in all relevant national mental health data collection.
- Advocate for policy change, bringing researchers, clinicians, and community together.
- Seek and develop philanthropic funds for eating disorder research.
- Collaborate with researchers, universities, research organisations, national peak bodies, the health and social sector, eating disorder community organisations, professional organisations and others, to advance eating disorder research in Australia.

Health and social sector agencies, health professional organisations & eating disorder community organisations:

- Promote and support the value of enquiry and innovation.
- Generate an organisational culture that values and uses practice based on evidence.
- Support research through investment funding based on provision of evidence-based practice and evaluation of outcomes.
- Advocate for policy change, bringing researchers, clinicians and community together.
- Establish effective pathways for knowledge translation and implementation.
- Collaborate with universities and other organisations that perform research to embed research and evaluation into the way services are delivered – providing access to ‘real world settings’.
- Collect and evaluate contact and usage data for the service.
- Provide student research project options.
- Co-host a local eating disorder research network.
- Develop strategies and provide advice on how representation of diversity in lived experience can be achieved.
- Showcase research through events and training delivered.
- Harness lived experience feedback and participation in activities.
- Ensure that services, programs and systems established within the agency or organisation support research.
- Ensure employees are provided with funded opportunities to engage with research and the knowledge and skills to participate.
- Establish innovative partnership with researchers, people with a lived experience and communities.
- Establish mechanisms to adopt appropriate and cost-effective knowledge and innovations.
- Share information and data where appropriate.

People with a lived experience (consumers/carers):

People with lived experience can choose to contribute to research and translation in a range of ways. All contributions are valuable, relevant and required. For example:

- Join a research project as a participant.
- Engage with service providers who demonstrate they utilise evidence in their practice.
- Advocate for the use of evidence in your recovery journey or the journey of a loved one.
- Insist that research is co-designed, co-produced, co-evaluated.
- Bring a lived experience voice to decision-making and the research process.
- Enhance knowledge and skills in relation to participation in and/or the conduct of research.

- Engage in innovative partnership with researchers, clinicians and others.
- Insist that providers create opportunities for professional development for those with lived experience wanting to undertake research.
- Use and disseminate research findings.
- Become a lived experience researcher.

Health professionals:

- Join a research project as a team member or participant.
- Use evidence in practice.
- Value and promote evidence-based practice (use of empirically supported treatment) and evaluation in practice.
- Contribute to research co-design, co-production, co-evaluation.
- Bring a clinician experience voice to decision-making and the research process.
- Engage in innovative partnership with researchers, people with a lived experience and others.
- Enhance knowledge and skills in relation to the delivery of evidence in practice.
- Enhance skills of appraisal and integration of evidence into practice.
- Undertake professional development to fill knowledge gaps.
- Use and disseminate research findings.
- Become a clinical researcher.

Government and funding agencies:

- Provide strategic and effective leadership.
- Underpin and align policies and practices with evidence and best practice research.
- Embed researchers in agencies to build workforce knowledge.
- Embed evidence-informed approaches in policy development.
- Analyse and achieve equity in funding for eating disorder research, commensurate with illness burden and impact on the community.
- Support collaborative research through investment and simplify funding arrangements and processes wherever possible.
- Allocate funding where services can demonstrate adherence to provision of evidence-based treatment that is proven to be effective.
- Support the development of necessary infrastructure e.g. digital platforms.
- Provide opportunities and incentives for research and pathways to impact health outcomes and wellbeing.
- Ensure research findings are used in the production of relevant government publications, health policy and health promotion.

- Establish mechanisms to integrate data and enable different parts of the system to share information.
- Monitor and evaluate services and systems in a robust and transparent way.

Philanthropic organisations and individuals:

- Invest in eating disorder research.
- Collaborate with governments, services, clinicians, people with a lived experience (consumers and carers), NGOs and other community-based organisations, schools and others, to support and promote eating disorder research.
- Provide eating disorder targeted grants, scholarships and research opportunities.
- Support the conduct of research that meets knowledge gaps and targets sector established research and translation priorities.
- Support the development of the research workforce, including clinicians and people with a lived experience.
- Provide support and funding to programs and projects, which have a demonstrated evidence-base.

Industry:

- Invest in research and development in prevention, intervention and knowledge translation and implementation.
- Partner with universities and other organisations that perform research, communities and the health sector to innovate.
- Promote and support validated and cost-effective innovations.

What will success look like?

Implementation of this Strategy requires commitment, and action, from all key stakeholders including researchers and clinicians, universities and research institutions, national peak bodies, key organisations such as eating disorder organisations, governments and funding agencies, people with a lived experience of eating disorder, philanthropy and industry.

What will be different for consumers and carers?

- Research that you have identified as being central to your experience and impacting on your wellbeing, will be prioritised by researchers and research funding bodies.
- You will be at the centre of research - participating in, and shaping the way, research is designed and conducted.
- Research will be carried out in places that are relevant to where you are living and accessing services – in schools, communities and primary care, as well as in specialist and non-specialist health, mental health and eating disorder services.
- Research will be culturally appropriate, accessible and relevant to you, your family and supports.
- Research will uncover answers that inform individualised treatments and a smoother journey through the health care system.
- Your individuality will be reflected in the research that is carried out in Australia.

What system improvements will we notice?

- All national mental health research programs will include eating disorders.
- Eating disorder research will be funded commensurate with illness burden.
- Research and evaluation will occur across the spectrum, in real-world settings, so that the system is continually reviewing, reflecting on and adjusting in response to evidence.
- There will be identified hubs, networks and partnerships focused around eating disorder research.
- The research workforce will grow, it will be led and supported by a culture that values creativity and innovation and leaders who work collaboratively to deliver research with impact.

How do we measure change?

Amount and type of research being conducted

- Amount and type of research being undertaken in the eating disorders field.
- Amount and type of research being undertaken to address priority knowledge gaps.
- Number and type of interventions/innovations that are developed from research.
- Time taken to translate research findings into policy and practices across health and other relevant sectors.

Investment in eating disorder research and translation

- Sources and investment in eating disorder research.
- Percentage of mental health research funding that is awarded to eating disorders research.
- Percentage of health research funding that is awarded to eating disorders research.
- Percentage of eating disorder funded research that includes translation and implementation.
- Number of targeted calls that include eating disorders.
- Rate of philanthropic investment in eating disorders research.
- Rate of industry investment in eating disorders research.

Translation & implementation

- Number and type of organisations that provide treatment or services that are evidence-informed/evidence-based.
- Number and type of eating disorder services that have embedded research and evaluation processes.
- Number and type of eating disorder services that have appropriately trained workforce and skills development programs.

Workforce

- People with eating disorders can access evidence-based treatment, delivered by health professionals who have appropriate education, training and skills.
- Researchers, clinical researchers, lived experience researchers are working collaboratively to generate research and to translate research into practice.

Partnerships, integration & co-production

- Number and type of co-production of research with researchers, clinicians and people with a lived experience – at all stages of the research process.
- Number and type of partnership/collaboration, funding and data sharing between research institutions, health services, community organisations and NGOs.
- Number and type of integration of researchers into clinical and community settings.
- Policy & data sharing
- Eating disorder research is integrated into mental health strategy, policy and procedure at all levels.
- National data sharing approaches that increase knowledge and application of research in Australia are established.

Monitoring and reporting

The National Eating Disorder Research & Translation Strategy needs to be a flexible and adaptive document that will be systematically reviewed to ensure alignment with shifting national priorities and research discoveries.

This would include:

- Development of a monitoring and reporting plan
- Annual monitoring and reporting
- A regular stakeholder workshop, at which progress against the strategy is discussed, and
- A regular priority setting process (at least every 5 years), which identifies the consensus research and translation priorities of consumers, carers and clinicians.

Glossary

Burden of disease (and injury) - The quantified impact of a disease or injury on a population using the disability-adjusted life years (DALY) measure [254].

Communities of practice - Groups of people who share a concern, or a passion, for something they do and learn how to do it better as they interact regularly [255].

Impact - The National Health & Medical Research Council (NHMRC) defines 'impact' as the 'verifiable outcome that research makes to knowledge, health, the economy and/or society', it is the effect of research after it has been adopted, adapted for use, or used to inform further research. It also includes research leading to decisions not to use a particular diagnostic, treatment or health policy [256].

Implementation Science - Rather than establishing the health impact of a clinical innovation, the goal of implementation science is to identify the factors that affect its uptake into routine use, then develop and apply strategies to overcome any barriers and enhance the facilitators, in order to increase the update of evidence-based clinical innovations [257].

Morbidity - Ill health in an individual, and levels of ill health in a population or group [254].

Rapid Review - "A rapid review is a form of knowledge synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting various methods to produce evidence for stakeholders in a resource-efficient manner."[156]

Research ecosystem - Elements of a research ecosystem include people (e.g., researchers, students, administrators, clinicians, people with a lived experience), governance structures (e.g., policies, agreements), physical capital (such as facilities and equipment), intellectual capital (knowledge, information, ideas), partners (such as industry, governments, research institutes, health services) and financial support (such as research grants, project funding) [258].

Research mechanisms - Research mechanisms support research activities – for example, research grants, research training, research supports (see below), researcher workforce development, cooperative agreements, fellowship programs, research centres, research awards, institutional and individual research training grants [259].

Research supports - Activities and practices that are designed to develop a researcher's skills, confidence and efficacy (e.g., formal and informal mentoring, writing groups, clinical supervision, instruction and guidance around research processes); or that support the conduct of research across services and systems (e.g., time to undertake research for clinicians, funding of research in a NGO).

Years lost to disability (YLD) - The number of years of what could have been a healthy life that were instead spent in states of less than full health. YLD represent non-fatal burden [254].

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