

Australian Eating Disorders Research & Translation Strategy **2021-2031**



Summary

Acknowledgements

Thank you to the people with a lived experience of an eating disorder, their families, friends and supports, as well as the clinicians, researchers, academics, policy makers and others from across Australia who have contributed their time, knowledge and expertise to the development of this important document. This ambitious work outlines our shared vision around better outcomes for people with eating disorders in Australia.

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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

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



State and Territory Eating Disorder Organisations



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.

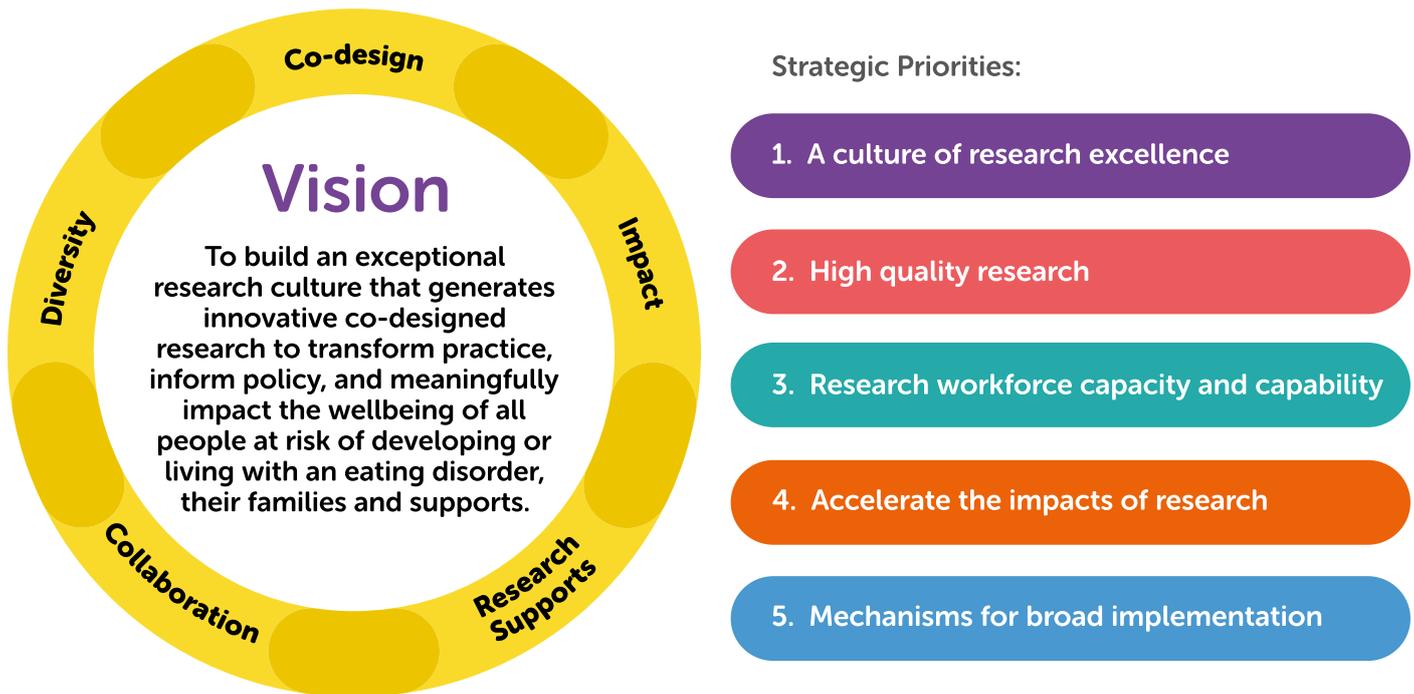
Audience

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.



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

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

Eating disorders are complex mental illnesses that affect people from early childhood to older age. They're estimated to affect at least 4-5% of the Australian population at any one time^{1 2} – that's 1 million+ Australians. They have high death rates – anorexia nervosa the highest among the mental illnesses – from medical complications and suicide^{3 4}.

Most people with eating disorders are not detected in primary care^{5 6} and do not access treatment. Of those who do, just 6-35% receive evidence-based treatment⁷. Research that occurs and can be applied in real world settings will improve access to evidence-based interventions.

Funding for eating disorder research in Australia is inadequate and is significantly less per affected person than for autism, schizophrenia or the depressive illnesses^{8 9}, despite comparable illness and cost burden¹⁰.

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 for all
- 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 death rates associated with eating disorders
- improve quality of life for all Australians who experience eating disorders, their families and supports.

“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.”

Bronny Carroll, Carer

How research and translation excellence will happen



1. Funding commensurate with the burden and impact of eating disorders.
2. Establishing structures and partnerships that support generation, translation and implementation of research across and between individuals, disciplines, organisations, sectors and community.
3. Growing the eating disorder research workforce (including clinical and lived experience researchers) and developing a strong research culture.
4. Engaging in co-design relationships that are a genuine exchange of knowledge, ideas and experiences.
5. Establishing eating disorder research and translation hubs, centres and networks which include metropolitan, regional, remote and very remote areas.

6. Clinical workforce development – to provide evidence-based treatment and to participate in research generation.
7. Conducting research that responds to knowledge gaps and priorities, is co-designed, innovative, rigorous, meaningful and covers all research areas.
8. Capitalising on the potential of big data and building on existing data sources.
9. Communicating clearly and broadly about eating disorders and research to build engagement and understanding.

“Our voice provides insight and a perspective that cannot be obtained from data alone.”

Shannon Calvert, Lived Experience Educator

Strategic Priority 1:

Support and generate a culture of research and translation excellence

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.

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).

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

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.

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,
 - 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

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

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.

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

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 & 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 through 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.

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 6).
- 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

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 [15].

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 [16].

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) [17].

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 [18].

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).

References

1. The Butterfly Foundation, The reality of eating disorder in Australia. 2020: Sydney.
2. Hay, P., Girosi, F. and Mond, J., 2015 Prevalence and sociodemographic correlates of DSM-5 eating disorders in the Australian population. *Journal of Eating Disorders*. 3(1):1-7.
3. Chesney, E., Goodwin, G.M. and Fazel, S. 2014 Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry*. 13(2):153-160.
4. Arcelus, J., et al., 2011 Mortality rates in patients with anorexia nervosa and other eating disorders: a meta-analysis of 36 studies. *Archives of General Psychiatry*. 68(7):724-731.
5. Ivancic, L., et al., 2020 Prevalence and management of people with eating disorders presenting to primary care: a national study. *Australian & New Zealand Journal of Psychiatry* DOI: 10.1177/0004867421998752
6. Hart, L.M., et al., 2011 Unmet need for treatment in the eating disorders: a systematic review of eating disorder specific treatment seeking among community cases. *Clinical Psychology Review*. 31(5):727-735.
7. Kazdin, A.E., Fitzsimmons-Craft, E.E. and Wilfley, D.E. 2017 Addressing critical gaps in the treatment of eating disorders. *International Journal of Eating Disorders*. 50(3):170-189.
8. Murray, S.B., Pila, E., Griffiths, S., & Le Grange, D. (2017). When illness severity and research dollars do not align: are we overlooking eating disorders? *World Psychiatry*. 16(3):321. <https://doi.org/10.1002/wps.20465>
9. Maguire S, 2018 Rethinking our response to eating disorders. *The Medical Journal of Australia*, (16). <https://insightplus.mja.com.au/2018/16/rethinking-our-response-to-eating-disorders/>
10. The Butterfly Foundation, Investing in Need - Cost-effective interventions for eating disorders. 2014. <https://butterfly.org.au/wp-content/uploads/2020/06/FULL-REPORT-Butterfly-Foundation-Investing-in-Need-cost-effective-interventions-for-eating-disorders-report.pdf>
11. Wenger, E., 2011 Communities of practice: A brief introduction. <http://hdl.handle.net/1794/11736>
12. National Health and Medical Research Council NHMRC 2021 Accessed: <https://www.nhmrc.gov.au/research-policy/research-translation-and-impact/research-impact>
13. Pandey, S.C. and Pattnaik, P.N. 2015 University research ecosystem: A conceptual understanding. *Review of Economic and Business Studies*. 8(1):169-181. DOI 10.1515/rebs-2016-0021
14. Pequegnat, W., Stover, E. and Boyce, C.A. 2011 How to write a successful research grant application. A guide for social and behavioural scientists. Springer Science & Business, New York.
15. Wenger, E., 2011 Communities of practice: A brief introduction. <http://hdl.handle.net/1794/11736>
16. National Health and Medical Research Council NHMRC 2021 <https://www.nhmrc.gov.au/research-policy/research-translation-and-impact/research-impact>)
17. Pandey, S.C. and Pattnaik, P.N. 2015 University research ecosystem: A conceptual understanding. *Review of Economic and Business Studies*. 8(1):169-181. DOI 10.1515/rebs-2016-0021
18. Pequegnat, W., Stover, E. and Boyce, C.A. 2011 How to write a successful research grant application. A guide for social and behavioural scientists. Springer Science & Business, New York.

