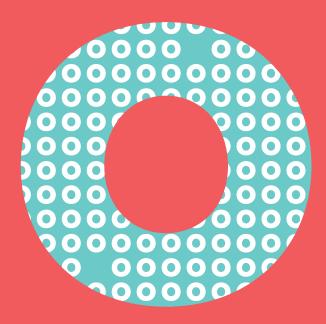


Re-thinking eating disorders from the inside out

Strategic Plan 2021 - 2026





Fast facts: Eating Disorders in Australia

†~1,900

~1,900 Australians are expected to develop anorexia nervosa every year



Eating disorders among men are significantly under diagnosed ~5%

~5% of Australians currently have an eating disorder





Body image ranked among the top 3 concerns for young people for the past nine years

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EXECUTIVE SUMMARY

InsideOut Institute is
Australia's first national
body for research and
clinical excellence in
eating disorders. With
resources, rigour and
perseverance we aim to
transform the treatment
landscape for eating
disorders in this country,
and ultimately find a cure.

We aim to drive change on four key pillars:

1. Research

2. Clinical Innovation

3. Education

4. Public Policy & Service Development

Since our launch in 2018, *InsideOut* has established an active and growing national team dedicated to transforming the prevention and treatment landscape for people with eating disorders in Australia. *InsideOut* was fortunate to have launched at a time of unprecedented government support for eating disorders. With federal, state and philanthropic funding, *InsideOut* has made substantive developments across our four core strategic pillars: research, clinical innovation, education, and policy & programs – our work occurs across the research, translation andimplementation pipeline.

We have undertaken seven federallyfunded national projects, including world-first research and clinical innovation projects, and developed and launched the first national research and translation strategy for any mental illness group in Australia. We have established national networks of researchers, clinicians and peole with lived experience (consumers and carers) to inform our work, which is firmly grounded in the principles of co-production. Our team members sit on Australian and international committees, consult at the highest levels of government on policy and practice guidelines, and are regularly invited to present at international conferences.

At a state level, our work has resulted in significant change to the treatment landscape in New South Wales. We spearheaded and authored the groundbreaking policy for treatment of people with eating disorders in NSW, the single largest and most ambitious eating disorder clinical redesign ever undertaken nation-wide. Evaluation of the first five years of the Plan has evidenced significant reform across the health system and highlighted the substantive contribution of local coordinators, deployed in every Local Health District (LHD), to promote local change which is transforming the experience of people with eating disorders and their families.

As Australia's national eating disorder research institute, all of our work is informed by research - the research we conduct and coordinate, as well as evidence generated nationally and internationally. Our in-house research program is ambitious. We are committed to translating research from laboratories into real world settings, and to ensure that evidence is broadly implemented across all areas within the health system for maximum impact. To that end, InsideOut has successfully implemented an in-house research lifecycle. At its simplest, this means that the work we do spans across the lifecycle of a research project: from conception and research innovation, through to experimental trials in real-world settings and the implementation of treatment that works across the health system to create system change. Co-design and production is a central part of the research cycle across all stages - from the research question, to the design of programs and interventions, to implementation and evaluation. We work in collaboration with experts in the field and, importantly, with people who are experts by lived experience of eating disorder.

We are currently leading the Medical Research Future Fund (MRFF) funded MAINSTREAM national centre for research & translation in eating disorders. It will build the first comprehensive population-based surveillance system of people with eating disorders, to track detection and intervention rates across the national health system and monitor outcomes; establish a national continuous lived experience lifetime survey for people with the illness, their family and carers; undertake translation-focused testing for scalable models of care for mainstream health; establish translation hubs in NSW, VIC, QLD to embed research expertise linked to front line health system design and delivery; develop health system and economic models to inform decision making about interventions.

Looking outside the box, we are partnering with high-profile research institutes nationally to explore novel therapies including a microbiome study and novel treatment options like cannabinoids, oxytocin and psilocybin. Alongside our national team, we have an established international research presence and global research partnerships worldwide, including collaborations with projects with Universities in London, Germany, New York and San Francisco.

InsideOut's eLearning suite has long been established as a go-to for clinicians seeking to increase their knowledge, skills and confidence in working with people who have eating disorders. Over 10,000+ clinicians have complete our eLearning programs over the past 4 years – including general practitioners and medical specialists, psychologists and other allied health professionals, dietitians and nurses – from public health, mental health, primary care and private health services.

A world-first eTherapy platform, designed

and built by *InsideOut*, aims to provide access to evidence-based treatment for people with eating disorders of all types and at any stage. Our programs have been trialed in real-world settings and demonstrate safety and impact. Most recently, our novel online CBT therapy for people with binge eating has shown significant reductions in core symptoms and is being implemented in headspace centres across the country. With philanthropic support, we are trailing virtual delivery of family-based therapy - direct into people's homes using telehealth - enabling people who live in regional and remote Australia to have access to evidence-based treatment that would otherwise be unavailable to them.

Change is impossible without a thriving workforce. At *InsideOut* we are determined to support the growth of the clinical and research workforce, to improve workforce capacity and

capability nationwide. In addition to our eLearning and face to face training for clinicians, we have established a growing Early Careers Researchers group, bringing together eating disorder researchers from across the country, with the core objectives of support and collaboration, which will strengthen and advance the field now and in years to come. Our Lived Experience Advisor is integrated across management and all pillars of the organisation.

2021 saw the launch of the Australian Eating Disorders Research & Translation Strategy. An initiative funded by the federal government and led by InsideOut, it provides the roadmap to establishing eating disorders as a national research priority. This landmark strategy was developed in collaboration with peak bodies, researchers and experts with lived experience. It represents an injection of hope and shared vision, uniting the voices of researchers and lived experience experts around the country. The five strategic priorities, recommendations and actions outlined in this document are underpinned by five principles and a vision to build an exceptional research culture that transforms lives.

InsideOut is well placed to deliver on these priorities and we are determined and hopeful in our objective to elevate eating disorders to become a national research priority. We are just getting started...

VISION

Rethinking eating disorders from the *InsideOut*

MISSION

To transform the prevention, early intervention and treatment landscape.

To cure eating disorders through innovative research, collaboration and an enduring path of inquiry.

VALUES

Transformation

Collaborate with the brightest minds, to transform research into inspired practice.

Excellence

Scientific rigour informs all of our endeavours.

Respect & Integrity

Committed to the highest standards of professionalism, ethics and personal responsibility, worthy of the trust people with lived experience place in us.

Courage

To be brave in our thinking, and bold in our steps.

Compassion

Understanding and empathy are at the core of our work.

Partnership

Co-production informs everything we do – embracing diverse voices for outcomes with impact.

WHAT IS AN EATING DISORDER?

"There is no school to attend to prepare anyone to care for someone with an eating disorder. No diploma or learnt degree. **Suddenly you are thrown** into a situation that feels like you're swimming upstream - with no land in sight"

Bronwyn, Carer

An eating disorder is a complex mental illness that can lead to severe and permanent physical complications, and even death.

The symptoms involve obsessive control of food, weight and body shape in an attempt to manage feelings or underlying emotional and psychological difficulties. However, these behaviours result in just the opposite: feelings of hopelessness and self-loathing.

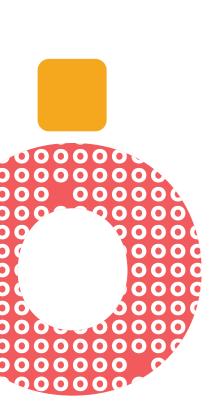
Eating disorders originate in the mind and manifest in the body. Medical complications include cognitive impairment, heart complications, growth retardation and osteoporosis. The isolating and tormenting nature of eating disorders can lead to depression, anxiety and suicide.

For the person affected, the eating disorder becomes unrelenting torture. For families and loved ones, the burden of eating disorders is one of the highest among all mental illnesses.

Eating disorders can affect anyone, from any cultural background. They can begin at any age, most commonly in adolescence.

Main types of eating disorders:

- 1. Anorexia Nervosa
- 2. Bulimia Nervosa
- 3. Binge Eating Disorder
- 4. ARFID (Avoidant and **Restrictive Food Intake** Disorder)
- 5. OSFED (Other Specified **Feeding or Eating Disorders).**





Australian eating disorders



?~200

~200 people are expected to die from bulimia



Eating disorders have one of the highest mortality rates of any mental illness



WHO WE ARE

InsideOut Institute comprises a team of expert researchers, clinicians and public policy-makers. We drive transformation of the eating disorder landscape through research and clinical innovation. We are committed to ensuring that every person with an eating disorder has access to the best possible care.

A four-pillar approach lies at the core of all of our activities:

1. Research

2. Clinical Innovation

3. Education

4. Public Policy & **Service Development**

Stakeholders

InsideOut Institute collaborates with a broad range of stakeholders dedicated to improving eating disorder care and leading change in the sector from the 'inside out'. We seek counsel from those with a lived experience, their families and carers, and value expert consumer consultants as members of our team. Eating disorder specialists working in clinical practice and research are pivotal to our mission and work. Our work is supported by NSW Ministry of Health, the Sydney Local Health District (SLHD) and the University of Sydney, as well as Federal research bodies and NGO's. We consult with a diverse range of peak health organisations and industry leaders to achieve our aims.

Together, our network has the capacity to continue to improve the quality of care for those with eating disorders, to deliver clinical innovation and lead scientific research in the sector.

Governance

InsideOut Institute is housed at the Charles Perkins Centre at the University of Sydney in collaboration with Sydney Local Health District (NSW Ministry of Health).

The Institute is supported by an Advisory Council comprising leading researchers, clinicians, policy makers, consumers, carers and experts in a range of disciplines.

Funding

InsideOut is funded by a variety of sources. We receive funding for research projects through peer reviewed grants from the National Health and Medical Research Council (NHMRC) and other Australian research funding agencies.

NSW Ministry for Health provides funding specifically for the purpose of developing and implementing policy and programs for eating disorders in NSW, including both service and workforce development. Philanthropy forms an increasingly important part of our funding stream, to enable innovative projects, and community engagement work. The Australian Government Department of Health has funded a number of national translational projects until June 2022.

in funding raised from research grants in the last 4 years



ACHIEVEMENTS

publications by InsideOut staff



Higher Degree students supervised by InsideOut staff

INNOVATION



eating disorder digital therapy made available in Australia



carers registered within 3 months of launching SupportED – our online program for carers



health professionals trained face-to-face since 2018

across 12 programs



conference presentations by InsideOut staff



Medicare providers upskilled to intervene early and provide evidence-based treatment

PUBLIC POLICY & SERVICE DEVELOPMENT



Australian Eating Disorders Research & Translation Strategy



iii 500

individuals representing 80 organisations, lived experience experts and researchers co-produced the Strategy and the national Top 10 research and translation priorities



to transform clinical services for people with eating disorders in NSW including FT ED coordinators in every district

OUR MAJOR ACHIEVEMENTS

Our Institute has secured the following major achievements in recent years under our four pillars of action.



1. Research

Since our launch in 2018 *InsideOut* has secured \$5.5+ million in research funding to develop innovative treatments for people with eating disorders and to trial them in real world settings, including being the primary recipient for the largest targeted research funding for eating disorders in Australia, the Million Minds Mental Health Research Mission in 2019.

One of our key objectives is to undertake innovative research that can be translated into clinical practice to continuously improve the prevention, early identification, and treatment of people eating disorders. In line with this, the *Institute* is currently conducting several world-first translational research projects, including a collaborative trial researching telemedicine delivery of family based therapy; evaluation of an online treatment program we developed for people with Bulimia Nervosa or Binge Eating Disorder (BEet); and we have validated an early identification screener (IOI-S) to help detect eating disorders early and online which is currently being trialled in primary care and headspaces services nationally.

As part of the Million Minds MRFF Mainstream Research Program we are also partnering with clinical and research leads in Victoria and Queensland to locate research capacity within frontline service settings and establish national research and translation hubs; at the moment we're doing this in partnership with the Centre for Excellence in Eating Disorders (CEED) Victoria, Queensland Eating Disorders Service (QUEDS), Eating Disorders Victoria (EDV) and Queensland Insitute of Medial Research.

We are also undertaking a range of research trials in collaboration with national and international experts – with Queensland Institute of Medical Research (QIMR) Berghofer and researchers in the USA, Sweden and Denmark, we are conducting world-first genome-wide association studies to identify the genes

associated with Anorexia Nervosa (the ANGI study) and other eating disorders (the EDGI study). With the Charles Perkins Centre Gut Microbiome and Nutritional Ecology nodes, QIMR Berghofer, Brain & Mind Centre we are conducting a number of studies seeking to examine microbiome, gut-brain axis and polygenic risk. We're exploring muscle dysmorphia in collaboration with University of Melbourne, suicidality with University of Western Australia and University of Wollongong, the impact of COVID-19 on people with eating diosrders or body image concerns; and we're collaborating with Kings College London to develop an instrument to identify early illness in children. We are working with epidemiologists and national data linkage specialists to evaluate 15 years of national health system data to establish the first National comprehensive and population-based Surveillance System of people with eating disorders; and we are establishing a National Eating Disorder Lived Experience Lifetime Survey, similar in scope to longitudinal feedback studies in other major illness groups.

In 2021,18 papers emanating from our research program have been presented at national and international eating disorder conferences, including the International Conference on Eating Disorders, hosted by the Academy of Eating Disorders, the Australian and New Zealand Academy for Eating Disorders Conference, the London Eating Disorders Conference, the Blackdog Mentally Healthier Schools Conference, and the Society for Mental Health Research Conference. Our researchers hold positions on peak eating disorder bodies such as the Academy for Eating Disorders and the World Psychiatry Association and maintain worldwide research partnerships, with current projects in London, Germany, New York, California, and Chicago.

We have also established an early career researchers program dedicated to supporting and developing emerging researchers, with more than 30 members from across the University of Sydney. The program aims to promote collaboration from the earliest stages of research and to develop the eating disorder research community.

2. Clinical Innovation

InsideOut is developing a world-first, national online clinic for eating disorders. Research shows early intervention is key to a successful recovery, and yet, Australia has no such framework in place. Our eClinic, which aims to fill this gap, will act as a "go-to" site for people with an eating disorder, delivering early screening, an online assessment and pathways to care. It will also act as a support and training hub for carers and health professionals. Ultimately, our eClinic will be paired with a walk-in clinic delivering evidence-based treatment packages.

Importantly, our eClinic has the potential to change the way access to specialist eating disorder treatment is delivered (and available) in Australia and significantly reduce the associated social and financial costs. Our eClinic builds on our existing eTherapies and trainings.

Our ongoing research into the effectiveness of our innovative online therapy program for bulimia and binge eating disorder (BEeT) has shown that our program reduces all key illness markers – binging, purging and general eating disorder symptoms – as well as being highly acceptable to clients. We have recently completed a trial of this accessible and scalable intervention in headspace and community mental health clinics and the program is now being implemented nationally. This program provides evidence-based treatment to people who would otherwise

be unable to access care, and offers isolated clinicians an evidence-based treatment referral option for their clients. A transdiagnostic eTherapy is under development and will be trialled in 2022. And for people who care for someone with an eating disorder, we have launched an online support package (SupportED) which is currently being evaluated, with excellent early feedback. *InsideOut* is also trialing Family-Based Treatment for adolescents with anorexia nervosa and their families, delivered by telemedicine to families living in rural and regional Australia in partnership with NSW Health and the University of California, and funded by Charles Warman Foundation, with results expected by 2023.

At *InsideOut*, one key point of difference is our commitment to advocating for funding for services across the health system. Driving change to the existing health system from the inside is essential to the delivery of quality and seamless care for the people whom we serve. This is especially true for eating disorders, which represent mental illnesses with multiple medical complications. This must be coupled with developing innovations and ensuring their translation within the system.

In line with this, *InsideOut* is developing a range of innovative resources to support general practitioners to identify and intervene sooner, and to deliver evidence-based care. These include a GP Microlearning project, the agile development of a co-designed Clinical Decision Support Tool for GPs (supporting GPs to make diagnoses and prescribe appropriate evidence-based treatment) and a Practice Management Toolkit customized to general practice software enabling integration of reports within the patient's medical record and including quality improvement practice solutions.



3. Delivering Education

InsideOut continues to spearhead innovation in the dissemination of workforce training focused on people with eating disorders.

We delivered the world's first interactive online training program in eating disorders in 2012, which has been proven to enhance healthcare professional knowledge and skills. Since then, we have been steadily building a hub of online training packages with expert and lived experience input, suitable for a range of audiences. Our training hub has delivered eLearning to over 10,000 clinicians - since 2020 we've rolled out our Essentials eLearning program to nearly 7500 clinicians - including GPs, medical specialists, psychologists and allied health professionals, dietitians and nurses – with funding from the Australian government. Upskilling the primary care and public health workforce to intervene early and provide evidence-based treatment across the system, is an essential workforce development function.

The *Institute* has become the go-to for eating disorder training in Australia – we have contracts with state and federal governments as well as peak bodies, for the delivery of broadscale online and face to face traing for the health workforce nationwide.

4. Public Policy & Service Development

InsideOut has an ambitious policy and service reform agenda and has delivered key policy documents for Australia and for NSW.

In NSW we've transformed the care of people with eating disorders through the delivery of a groundbreaking statewide Service Plan, released by the Ministry of Health at Parliament House in June 2021, with implementation activities occurring through to 2025. The comprehensive Service Plan builds on our earlier policy and implementation work and requires whole of health reform, driven centrally and implemented locally, to prepare and equip the NSW Health system to identify, provide access to, and treat people with eating disorders. The Service Plan has enabled the development of new hospital and community services for people with eating disorders and is the single largest and most ambitious eating disorder clinical redesign ever undertaken nationwide.

InsideOut advocated for and authored the Service Plan, in partnership with NSW Health and in consultation with local health districts and other key stakeholders, securing \$46 million to implement its delivery over five years. This includes a new increase of \$4 million per year recurrently to deliver clinical services, as well as funding to make all local Eating Disorders Coordinators full time.

Through the previous plan, we utilised service design and change strategies and principles to achieve reform on all three service targets – emergency departments, hospital admissions and community health pathways – by supporting local eating disorders coordinators, medical leads and their local health districts and specialty health networks to improve access and quality of care. The new Service

Plan, along with the previous 5-year plan, has changed the treatment landscape for people with eating disorders and their families and supports in NSW.

Nationally, InsideOut was the architect and author for the recently released Australian Eating Disorders Research & Translation Strategy 2021-2031. Funded by the Australian Government Department of Health, this Strategy represents the collective thinking of hundreds of individuals and keystakeholders nationally, in a co-design project that was over 2 years in the making. This is an important milestone for the eating disorder community and for the millions of Australians who experience an eating disorder, their families and supports, because it provides the roadmap to establishing eating disorders as a national research priority. As part of this project, we commissioned a Rapid Review of the existing evidence base and a James Lind Alligned prioritiy setting process, to establish the Top 10 eating disorder research and translation priorities for Australia.

Our Institute frequently consults at the highest levels of government. Two of our executive team sit on the National Eating Disorder Collaboration (NEDC), which advises on the national health agenda. Our Director and National Programs Manager sat on the national MBS Advisory committee that developed the transformative 2019 Medicare items for eating disorders. We have developed a range of resources to help support GPs and mental health clinicians accessing these items.

InsideOut publishes clinical policy, guidelines and codes of conduct for industry, including National Fitness Guidelines, Hospital and Community Treatment Policies and Professional Care guidelines.



		Early development	Under trial	Available
Research	Mainstream – Establishing a National Surveillance System for Eating Disorders, Health Economic Analysis, Lived Experience Integration and Translation into Practice	√	√	
	COVID-19 Impact on people with Eating Disorders	√	√	√
	Microbiome in Restrictive Eating	√		
	FMRI Studies in patients who Binge Eat	√		
	Eating Disorders in Obesity Treatment – individual participant data meta-analysis to determine predictors of eating disorder risk during obesity treatment	✓	√	
	Excessive Exercise Assessment and Intervention in Eating Disorders and Muscle Dysmorphia	✓	√	
	Psychedelics (Psilocybin) & Anorexia Nervosa	√	√	
	Cannabidiol & Anorexia Nervosa	✓		
	Use of Stimulants in Eating Disorders	✓		
Clinical Innovation	BEet - An Online Treatment Program for Bulimia Nervosa and Binge Eating		√	
	A Transdiagnostic eTherapy Toolkit – Improving access to brief interventions	√		
	IOI Screener for Early Identification - Online and in-person		✓	✓
	Maudsley Family Based Treatment for Adolescent Anorexia Nervosa delivered by Telemedicine into the home	√	√	
	SupportED – Online Support Package for people who care for someone with a Lived Experience of Eating Disorders	√	√	
	GP Digital Decision Tool	✓	✓	
	Food Monitoring App	✓	✓	
Education &	Microlearning for GPs	✓	✓	
eLearning	EducatED online training for education staff	✓	✓	
	A suite of elearning and face to face professional development in inpatient management, community based treatments (FBT, CBTe and SSCM) and dietitian specific training			√
Policy	National Top 10 Research Priorities			✓
	Implementation of the NSW Statewide Service Plan for people with Eating Disorders 2021-2025			√
	Pregnancy & Eating Disorders Guidelines	✓		
	Diabetes & Eating Disorders Guidelines	✓		
	Managing Complex Co-morbidity Guidelines	✓		
	Managing Eating Disorders in the Community	✓		
	Inpatient Management of Adults with Eating Disorders Toolkit	√		
	National Fitness Guidelines			✓
	Inpatient Nursing Care Guidelines	✓		

STRATEGIC DIRECTION

Our strategic directions going forward will be driven by our four key pillars:

1. Research

AIMS	ACTIVITIES	OUTCOME/IMPACT
Conduct co-designed, innovative, high impact research and translational	Advocate for and create novel funding and research collaborations and partnership opportunities.	Increase in collaboration and partnership activities. Increase all category funding into eating
outputs that change		disorder research & translation activities.
people's lives.	prevention, early identification, treatment, recovery, support,	Increase published output of ED related research & translation activities.
	improving outcomes and ultimately working towards finding a cure.	Increase the HDR and ECR workforce in ED research.
	 Embed co-design and production principles across all research and translation activities. 	Demonstrate and disseminate viable co-design practices.
	Disseminate findings and contribute to the evidence-base nationally and internationally.	Increase the clinical and lived experience research workforce.
		Contribute to the national implementation of the AEDR&T Strategy.
	Conduct and translate research focused on embedding high-quality evidence into routine practice.	The Institute is recognised as a leader in co-designed, translational eating
	Work in alignment with the Australian Eating Disorders Research & Translation Strategy.	disorder research excellence.

2. Clinical Innovation

AIMS	ACTIVITIES	OUTCOME/IMPACT	
Translate research into inspired clinical practice – so everyone living with or affected by an eating disorder has access to evidence-based care.	 Develop a comprehensive eClinic. Provide access to digital therapies nationally, including embedded within existing health pathways and teams. 	Provide digital therapies and tools that reduce illness morbidity and improve outcomes for diverse audiences, at scale across Australia.	
	Establish the Walk-In Clinic to provide comprehensive assessment and treatment planning and deliver	Digital therapies and tools are embedded in and accessed, via established health pathways nationally.	
	evidence-based packages. 4. Embed research expertise with frontline health system design and delivery through translation hubs nationally.	The Institute is recognized as a leader in digital health innovation.	

Strategic Direction

(Continued)

3. Education

AIMS

Increase capacity and capability of the clinical, research and lived experience workforce through the creation and provision of high quality, evidence-based workforce development activities.

Inform and influence public

reform nationally.

policy and service development

ACTIVITIES

- Grow the HDR program, ensuring sustainability of supervision and support structures for students.
- Grow the ECR development program to support and develop emerging researchers from all relevant disciplines, including clinical and lived experience.
- 3. Translate research findings into high quality evidence-based education programs.
- 4. Train the national health workforce.

OUTCOME/IMPACT

The eating disorder knowledge to practice gap is diminished.

The Institute is a recognised leader in HDR, ECR workforce development and support.

The national clinical, research and peer workforce skilled in eating disorders grows in number and capacity.

Clinicians in general health and mental health settings will use evidence-based strategies in their everyday practice.

4. Public Policy & Service Development

AIMS

ACTIVITIES

1. Partner with state, territory and federal governments, and service providers nationally to design, fund and establish services.

- 2. Participate in committees, working parties and reference groups, within eating disorders, health and mental health sectors nationally to create impactful policy and practice standards.
- Advocate for and support the inclusion of eating disorders in relevant public policy and strategy.
- 4. Initiate prevention, health promotion and stigma reduction campaigns.

OUTCOME/IMPACT

Eating disorder care provision becomes part of the core business at all levels of health care.

The Institute's research and translation expertise informs the development of evidence-based eating disorder policy and quality service provision.

Increased relevance and relationships lead to greater engagement in key stakeholder activities.

Eating disorders are included in relevant public policy and strategy documents.

Funding for eating disorder research, prevention and intervention increases.

5. Science communication

Provide a nationally recognised

research-based information

authoritative source of

about eating disorders.

AIMS

ACTIVITIES

Ensure active media and social media presence, representing our research, translation and implementation activities to the community.

 Develop, refine and expand the Institute's website as an eating disorder evidence hub with relevance to a wide range of audiences.

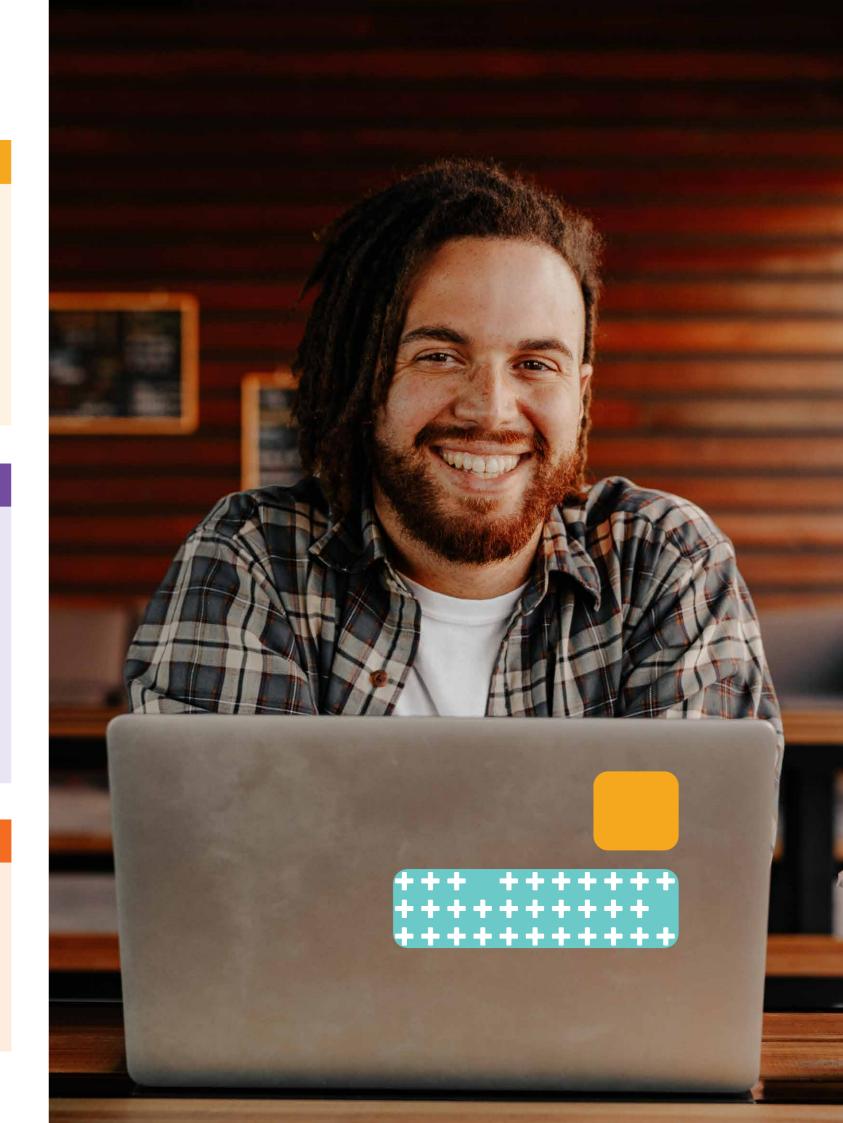
OUTCOME/IMPACT

Increased reach and engagement.

Stigma is reduced and understanding increased.

Our research and translation activities are represented in media content across all platforms.

Eating disorder research increasingly informs the national health and mental health conversation.











InsideOut Institute

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