# **INSIDE OUT** Institute for Eating Disorders

Re-thinking eating disorders from the inside out

Strategic Plan 2018 - 2020





www.insideoutinstitute.org.au

# VISION To provide every person with an eating disorder access to the best possible care.

Fast facts: Eating disorders in Australia

# **i~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**

We are leaders in affecting change in our field. Our work has already resulted in significant change to the treatment landscape in New South Wales. We spearheaded and authored the groundbreaking policy for treatment of eating disorders in NSW, launched at our premises with then NSW Health Minister, The Hon. Jillian Skinner MP and then NSW Mental Health Minister, The Hon, Kevin Humphries MP in September 2013. We advocated for, and secured \$17.3 million over five years, and ongoing funding of \$5.6 million per year, for the development of new hospital and community services for eating disorders - the single largest and most ambitious eating disorder clinical redesign ever undertaken nation-wide – performed by our team.

We have an established international research presence and global research partnerships worldwide, including current projects with the Universities of London, Germany, New York and San Francisco. 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.

In the past five years alone, we have published more than 100 research papers on treatments for eating disorders. Our research covers psychoneuroendocrine treatment of Anorexia Nervosa, the world's first trial of psychotherapy for chronic Anorexia Nervosa, and online treatments for Bulimia Nervosa and Binge Eating Disorder. Our publication of more than 16 papers on eating disorders in males in recent years has consolidated our leadership in this research area, debunking the myth that males rarely experience eating disorders. Moreover, our team has also developed and validated a world-first staging model of Anorexia Nervosa.

Our eTraining and therapy centre is the world's first for eating disorders, developing novel eLearning and eTherapy programs.

Innovative platforms to train staff and treat patients who would otherwise be unable to access quality care has emerged as a vital element of InsideOut's approach.

So what will it take to drive change from the 'inside out'? An ambitious research agenda, inspired public policy, clinical innovation and consistent translation of research findings and innovation into accessible treatment.

Our immediate challenge at *InsideOut Institute* is to build a resource base to deliver leadership across all of these domains and to develop a research centre of excellence. To do this, we must continue to forge partnerships with the healthcare workforce, philanthropy, service providers, other agencies in the sector, and most crucially, government. To fund ongoing research, clinical innovation and policy development we must also reinvigorate revenue with financial support from medical, industry and philanthropic sources.

# VISION

To provide every person with an eating disorder access to the best possible care.

# MISSION

### Our mission is:

- 1. To transform the treatment landscape for eating disorders in Australia.
- 2. To find a cure through innovative research, collaboration and an enduring path of inquiry.

# VALUES

### Transformation

Collaborate with the brightest minds, to transform research into inspired clinical 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 patients and carers place in us.

### Courage

To champion unpopular causes. To be brave in our thinking, and bold in our steps.

#### Compassion

Understanding and empathy are at the core of our work.



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# WHAT IS AN EATING DIS<sup>O</sup>RDER?

"An eating disorder invades your entire mind and devastates all that is good and colourful inside of you. It is unrelenting torment, from which you cannot escape, day or night. It tells you what to do and what to think, every minute of the day. And you obey, because you will do anything you can to make the voices stop, if only for a moment."

Steph, 19 years

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 illness is one of the highest among all mental illnesses.

There are many common myths involving eating disorders. The stark reality however, is that eating disorders are not a choice, nor a diet, or a desire to become healthy. They do not affect only girls and young women. Rather, eating disorders can affect anyone, from any cultural background. They can begin at any age, most commonly in adolescence.

## There are four main types of eating disorders:

- 1. Anorexia Nervosa
- 2. Bulimia Nervosa
- 3. Binge Eating Disorder
- 4. OSFED (Other Specified Feeding or Eating Disorders).



## Fast facts: Australian eating disorders

# ~450

~450 people are expected to die from Anorexia Nervosa every year

# 200

~200 people are expected to die from bulimia nervosa every year

# ~1 in 5

~1 in 5 of those deaths is expected to be by suicide

**\*%\*\*** 



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

# WH<sup>Q</sup> WE ARE

InsideOut Institute comprises a team of expert researchers, clinicians and public policy-makers dedicated to solving the tyranny of eating disorders. We drive the 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**

### **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.

### **Our History**

In 1995, Professors Stephen Touyz and the late Professor Peter Beumont founded The Centre for Eating and Dieting Disorders (CEDD) to further research and treatment for eating disorders in Australia.

From its fledgling beginnings, the centre was re-launched in 2005 when the NSW Ministry of Health provided the first funding for a single staff member and a first project – training GPs in the treatment of eating disorders.

Over the past 12 years, CEDD has witnessed steady growth, with its staff, researchers and project positions expanding to over 30, and projects spanning policy and program development, research, national education and training.

In 2018, CEDD became the InsideOut Institute. The re-branding of our organisation coincided with the growth of our vision to become a national leader in research and clinical innovation. The name InsideOut reflects our determination to bring eating disorders out of hiding and into the light of public discourse. Our name reflects our goal – to transform the treatment landscape and reduce the personal toll of eating disorders by ensuring the best possible care and support is available to all.

# ACHIEVEMENTS

## The InsideOut Institute has:

## RESEARCH

**100** 

Published over 100 research papers in the last 5 years

**5** \$2m

Secured \$2 million in grants in the last 5 years

## EDUCATION

2776

Trained 776 health professionals face-to-face

02,183

Enrolled 2,183 users across 7 courses in our online training programs

**1,035** 

Established a 1,035 member-strong network

## CLINICAL INNOVATION



Secured funding for 9 new specialist, long-stay hospital beds for critically ill patients

\*20

Secured funding for 20 new day program places in hospital and community settings in NSW

K

Developed an innovative online therapy for binge eating illnesses

## PUBLIC POLICY

🗿 \$17.6m

Attracted \$17.6 million funding for public services

# OUR MAJOR ACHIEVEMENTS

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



### 1. Research

Over the past five years, we have published more than 100 papers and secured over \$4 million in research funding to explore innovative treatments for eating disorders.

Our Institute has conducted several world-first research projects, including an NHMRC-funded trial of psychotherapy for chronic Anorexia Nervosa; the development of online treatment programs for Bulimia Nervosa and Binge Eating Disorder; and the world's first trial of oxytocin treatment in anorexia nervosa. We participated in research collaborations across Australia, the US and Europe.

Over the past two years, more than 30 papers emanating from our research program have been presented at national and international eating disorder conferences, including ICED, AED and ANZAED.

Our team members hold positions on peak medical bodies (Academy for Eating Disorders, World Psychiatry Association) and regularly present at international conferences (International Conference on Eating Disorders, Eating Disorder Research Society Meeting). Furthermore, we have established worldwide research partnerships, with current projects in London, Germany, New York and Chicago.

## 2. Clinical Innovation

*InsideOut* remains at the forefront of new and emerging technologies in the delivery of quality, clinical care.

We are launching a world-first, national online clinic for eating disorders in 2018. 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, online treatment and pathways to care. It also acts 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 packages.

Importantly, our eClinic has the potential to change the face of eating disorder care in Australia and significantly reduce the associated social and financial costs.

Our eClinic builds on our existing eTherapies and Trainings. In 2017 we published the first results from our innovative online therapy program for bulimia and binge eating disorder (BEeT). Our 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. Data reveals our program reduces all key illness markers - binging, purging and general eating disorder symptoms. We also have an additional three new online treatment programs underway.

In New South Wales, we sourced funding and developed an innovative, long-stay hospital unit for critically ill patients, along with multiple day programs in hospital and community settings across the state. InsideOut secured \$17.3 million from NSW Health over five years (2013-2018), with ongoing recurrent funding of \$5.6 million per annum to transform the treatment landscape for eating disorders in NSW. This represents years of tireless advocacy and clinical planning work by our team, and the single biggest clinical investment in eating disorders in Australia. We have delivered these clinical services on time and within budget.

At *InsideOut*, our key point of difference is our commitment to advocating for funding for services across the health system. We believe the existing health system is the largest and best placed structure to provide care for people with mental illnesses. This is especially true for eating disorders, which represent mental illnesses with multiple medical complications.

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 must be coupled with developing innovations *outside* of the system, ensuring their translation within the program for change is complete.

### **3. Delivering education**

*InsideOut* has been spearheading innovation in the dissemination of workforce training in eating disorders for years.

## 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.

We have since been steadily building a hub of online expert training packages in eating disorders. In the past year alone, we have developed four innovative, interactive online programs, and made them broadly available to clinicians throughout Australia and beyond.

Our Institute has become the go-to for eating disorder training in Australia, with contracts with state governments and peak bodies for the delivery of online training, to large-scale workforces nation-wide. We have more than 1,000 clinician members around Australia who regularly access our website for professional development and training.

Over the ensuing two years, we will deliver face-to-face training in evidence-based practice to more than 1,000 Australian clinicians.

Workforce training is pivotal to the NSW Service Plan which we developed and implemented. This initiative has involved the appointment of 16 local coordinators to manage training in every district state-wide.

## 4. Changing Public Policy

The *InsideOut Institute* has transformed eating disorder care across New South Wales through the delivery of a groundbreaking service plan, released by the Ministry of Health at our premises in 2013, with implementation through to 2018. The landmark policy mandates eating disorders, for the first time, will be seen as core business by the health system in NSW.

InsideOut advocated for, and authored the plan, securing \$17.3 million to oversee its delivery over five years, and \$5.6 million per year recurrently to deliver services. This policy has changed the treatment landscape for these illnesses. Patients and their families in NSW can no longer be turned away from local hospitals and mental health clinics. This policy is an Australian-first.

Our Institute frequently consults at the highest levels of government. Two of our senior staff have sat on the National Eating Disorder Collaboration (NEDC) for the past four years, which advises on the national health agenda.

Our team also sat on the steering committee responsible for developing the world's newest clinical guidelines for the treatment of eating disorders, which was published by the Royal Australian and New Zealand College of Psychiatrists in 2014.

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



## Products delivered in 2017

		Early development	Clinical trial/ Evaluation	Available
Clinical Innovation	BEet	✓	$\checkmark$	
	Oxytocin for AN	✓	✓	
	Carers skills training	✓		
	Body image resilience	✓		
	Food monitoring app	✓	✓	
eTraining for health professionals	СВТ	✓	✓	$\checkmark$
	FBT – The Basics	✓	✓	$\checkmark$
	FBT – Advanced	✓	✓	$\checkmark$
	Inpatient Management	<i>✓</i>	<i>✓</i>	<ul> <li>Image: A start of the start of</li></ul>
Policy	NSW Service Plan	<i>✓</i>	<i>✓</i>	<ul> <li>Image: A start of the start of</li></ul>
	Fitness Industry Guidelines	<i>✓</i>	<i>✓</i>	<ul> <li>Image: A start of the start of</li></ul>
	Nurses Guidelines		<u></u>	
	Code of Conduct			

# STRATEGIC DIRECTION

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

1. Research 2. Cl	nical Innovation 3. Education	4. Public Policy
Research		
AIMS	ACTIVITIES	OUTCOME/IMPACT
Support the best research into eating disorders across Australia.	1. To secure funds to support research teams across Australia to conduct high quality research into eating disorder prevention and treatment.	A 200% increase in the views the of our eLearning and evidence-based practice tools by general and mental health clinicians.
Conduct, translate and disseminate research evidence and innovation	2. Sustain targeted and innovative research into the aetiology, treatment and prevention of eating disorders.	A minimum of 28 research papers published per year. A 50% increase in base research
into the daily practice of front-line clinicians.	<ol> <li>Translate research findings: communicate domestic and international findings. Develop tools to transform everyday clinical practice into evidence-based practice – expand our online trainings and tools.</li> </ol>	funding.
	<ol> <li>Distribute learning's from international experts through various channels i.e. podcasts, e-learning.</li> </ol>	
	4. Secure a program grant.	
	<ol> <li>Produce successful research grant applications.</li> </ol>	

## 2. Clinical Innovation

### AIMS

To make available to every person with an eating disorder and their carers, early diagnosis, guidance through the health system and equitable access to evidence-based treatment packages.

### ACTIVITIES

- Build an eClinic: a suite of online treatment programs linked to a centralised clinical hub, offering early assessment and diagnosis, treatment planning and pathways.
- 2. Partner with telemedicine (video link up) outreach teams to provide training and resources for rural and regional clinicians.
- 3. Build a Walk-In Clinic to provide comprehensive assessment and treatment planning and deliver evidence-based packages.

### OUTCOME/IMPACT

Earlier diagnosis in the illness journey.

Decrease in carer burden, enabling greater ease to navigate the health system.

More people able to access evidence-based treatments.

Occasions of care for people with eating disorders to show an increase in each of the Local Health Districts.

An open and running clinic in 2020.

# **Strategic Direction** (Continued)

## **3. Education**

AIMS	ACTIVITIES	OUTCOME/IMPACT	
Make the issue of eating disorders an everyday conversation, for everybody.	<ol> <li>Establish an active media and social media presence, disseminating facts and messages to alter perceptions and change minds.</li> </ol>	Reduced stigma and shame.	
		Eating disorders part of the national conversation.	
Driven by the principles	<ol> <li>Launch <i>InsideOut Day</i> – a public day of action and awareness for eating disorders.</li> </ol>	Increased help-seeking behaviours.	
of knowledge translation, we will train the workforce in the most up-to-date, evidence-based practice.		Clinicians in general health and mental health settings will using evidence-based	
	<ol> <li>Translate research findings into training programs, both online and face-to-face, and run workshops to up-skill the national workforce.</li> </ol>	strategies in their everyday practice.	
		An increase in occasions of care for people with eating disorders in rural and remote area.	
	4. Build our online resource hub for GP's and other health professionals – enhance access to instruments for each health profession, assessment tools, decision trees, e.g. referral forms, fact sheets, online training, online evidence-based treatments to be delivered by general health and mental health professionals in a supported, online treatment modality.	Epidemiology studies to demonstrate increased recovery rates, reduced chronicity rates and reduced mortality for individuals living with eating disorders.	
	5. Quarterly dissemination of key international research findings as a translational tool for informing and improving eating disorder knowledge for academics and		

clinicians.

# **Strategic Direction** (Continued)

## 4. Public Policy

AIMS	ACTIVITIES	OUTCOME/IMPACT	
Provide coherent and integrated public policy to address the treatment of eating disorders in all relevant sectors and all states and territories nation-wide.	<ol> <li>Publish position papers for the general public on body, weight, eating and health that shift the nature of the debate.</li> </ol>	Eating disorders recognised as a national priority and resourced accordingly.	
	2. Inform the non-converted: collaborate to develop a series of public lectures by eating and weight disorder specialists, delivered specifically for public opinion makers (fashion editors, politicians, journalists, media managers).	Eating disorder prevention and messaging strategies integrated into the approach to prevent and reduce obesity.	
		Significant increase in government investment in eating disorders.	
	3. Continue to develop relationships with Government.		
	<ol> <li>Advocate for integrative and comprehensive public policy and messaging across eating disorders and obesity.</li> </ol>		
	<ol> <li>Publication of evidence-based reviews relating to matters of public interest.</li> </ol>		
	6. Publication of codes of conduct, guidelines and policy.		



# **INSIDE OUT** Institute for Eating Disorders





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