

National Research and Translation Strategy for Eating Disorders

Summary of Phase One of National Consultation

June 2019

Thank you to all those who participated in the first round of national consultations to develop the first National Research and Translation Strategy for Eating Disorders.

With this first round of consultations nearing completion, we can now start to shape a roadmap for future research into eating disorders and its translation into quality care.

Throughout May, consultations were held in every state and territory (NT to be held shortly), to pull together the **key priorities from across the country**. The consultations were truly collaborative and cross-sectorial, and we are grateful to all involved for giving so generously of their time and thought.

Consultations were attended by consumer and carer representatives, clinicians and service providers both public and private, academics and researchers, and representatives from both our state and national mental health commissions. State governments and the federal health department sent representatives to each consultation.

Historically, eating disorders have had one of the lowest research dollar spends per affected individual. This lack of investment has had downstream effects on the workforce responsible for research and care delivery in this sector, and most pivotally, on the care people with eating disorders and their carers receive.

The aim is to develop a strategy that will drive change for eating disorder care, and the outcomes we can expect from that care. **The scope of the strategy addresses prevention, early intervention and treatment of eating disorders.**

This brief provides a summary of the key themes emerging from the first round of consultations. It is not designed to be an exhaustive summary, but rather, a high-level synthesis of concepts that were repeatedly heard across all states and territories.

Over the coming months, InsideOut will be holding additional consultations for those unable to attend in their capital cities, and some individual consultations with stakeholders and leaders in research and translation. We will be in regular contact and you will have access to drafts of the document as it develops for your feedback.

Emerging Themes

Consultation participants identified gaps and developed priorities across three domains – research, translation and the implementation of evidence. Identification of research priorities emerged across prevention, early intervention and the treatment of eating disorders.

Research gaps and priorities:

- A fundamental gap and future priority is the level of investment in research in eating disorders within Australia, as the previous level of investment has led to major knowledge gaps across almost all domains
- No single knowledge domain emerged as well-researched, most emerged as lacking knowledge or piecemeal
- Strategic structural investment will be necessary to build the research workforce and the number of research trials nationally to encourage quality workers into this field and to retain them
- Competitive funding schemes need to be targeted to routinely include eating disorders as part of their priority areas and for eating disorders to be included among the major mental illnesses for investment
- There is good existing evidence about elements of treatment that are effective in eating disorders, and a number of well researched evidence-based therapies; translational research funding needs be prioritised to tailor this evidence to mainstream health settings, evaluate and implement

- **Funded research has been identified as being required for**

The classification of eating disorders

Epidemiology of eating disorders

Distribution and determinants of eating disorders

Prevention programs that target the developmental trajectory

Impact of targeting risk factors for eating disorder across the lifespan

Longitudinal studies of risk and onset

Public health messaging around food and weight for youth and general population, and the impacts of messaging

Impact of public health messaging and prevention programs for obesity on risk for eating disorders

Impact of general mental health prevention programs on risk for eating disorders

Prevention program aimed at parents and carers

Existing prevention programs

Effective screening and early detection processes for eating disorders, particularly in mainstream health settings, schools, and primary health

The development of interventions that work in the early stages

Effective interventions for cohorts, including Indigenous populations, LGBTQI, CALD, and comorbid populations

Treatment for ARFID and emerging eating disorders

Digital platforms for care delivery

Effectiveness of hospital-based treatments

Research on the experience of families and carers

Personalised medicine

Translation gaps and priorities:

- Genuine co-design of research from inception including consumers, carers, government where relevant, and care delivery staff from the delivery context
- Research in real world settings (co-location of research in treatment settings) ensuring treatments will work with populations presenting to care
- Research to address accessibility and affordability of treatment with new models
- Current funding for research is disconnected from clinical practice
- Research design and statistical methods that allow for variation within the sample and the evaluation of the application of personalised medicine
- Mechanisms and funding to evaluate the impact of investment in care and efforts to drive evidence into practice
- Journals available to publish in and nature of successful publications determine research agenda
- People with lived experience on editorial boards for journals to speak to relevance of interventions
- Tools to capture data at point of care
- Tools to access and analyse data already existing in the system
- Strategies are required to make evaluation part of routine practice e.g. designated funded research hours in clinical practice
- 'Translation' officers whose job is to increase evidence in practice and support clinicians to conduct research
- There is a lack of national evidence-based care standard

Evidence Implementation gaps and priorities:

- The health workforce is not research implementation trained or focused – the scientist practitioner model in university and training programs needs be more broadly adopted
- Leadership in services to instil a culture of evidence implementation
- Ensure systems support research data collection producing good data to drive quality improvement
- Embed evidence implementation as part of core business in services (e.g. KPIs)
- Build a trained and experienced workforce through workforce training
- Hubs or centres of excellence are needed to train the workforce, support evidence implementation and maintenance throughout the system
- Designated positions within care delivery teams to support research and implementation
- Development of a peer workforce in eating disorders

Next Steps...

- Consultations will continue with those that were unable to attend
- The Advisory and Jurisdictional Boards will meet
- A literature review of existing national and international strategies will be conducted
- The draft strategy will begin development in the second half of this year
- Additional contributions can be made to the strategy by completing a survey at this link https://sydneypsy.qualtrics.com/jfe/form/SV_5BXfhSkymMCbGa or by emailing nationalstrategy@insideoutinstitute.org.au.

Thank You to All Involved in Phase One

Many organisations below sent more than one representative. In addition, many clinicians, carers and consumers treating, living with and advocating for this illness group in the community attended the consultations.

ACT Health
ACT Working Group for Eating Disorder Health Care Services
Adult Mental Health Services
Alfred Child & Youth Mental Health Service (CYMHS)
Austin Health
Australia & New Zealand Academy for Eating Disorders (ANZAED)
Australian National University (ANU)
Balanced: Mind Body Life
Barwon Health
Bendigo Adult Community Mental Health Team
Bendigo Health Child and Adolescent Mental Health Services (CAMHS)
Beyond Blue
Body Image Eating Disorders Treatment & Recovery Service (BETRS)
Brisbane City Doctors
Butterfly Foundation
Canberra Health Services (CHS)
Capital Health Network
Carers ACT
Central and Eastern Sydney Public Health Network (CESPHN)
Centre for Clinical Interventions (CCI)
Centre for Mental Health Learning (CMHL)
Child and Adolescent Mental Health Service (CAMHS)
Child and Youth Mental Health Service (CYMHS)
Childrens Hospital at Westmead
Clare House Child & Adolescent Mental Health Services (CAMHS)
Deakin University
Department of Health
East Metropolitan Youth Unit (EMyU)
Eating Disorders Families Australia (EDFA)
Eating Disorders Program (EDP)
Eating Disorders Queensland (EDQ)
Eating Disorders Victoria (EDV)
endED
Fiona Stanley Hospital
Flinders University
Gold Coast Primary Health Network
Headspace
HelpingMinds
Hollywood Clinic
Hunter New England Health (HNELHD)
La Trobe University
Mental Health Council of Tasmania (MHCT)
Mental Health Network
Mental Illness Education ACT (MIEACT)
Mind Body Well
Ministry of Health
Monash Health
Monash University
National Eating Disorders Collaboration (NEDC)
National Mental Health Commission
Newcastle Eating Disorders Day Program
North Metropolitan Health Service (NMHS)
Nourish. Nurture. Thrive.
Office for Mental Health & Wellbeing
Orygen Youth Health (OYH)
Peter Beaumont Unit (PBU)
Queensland Eating Disorder Service (QuEDS)
Queensland Mental Health Commission
Ramsay Health Care
Royal Children's Hospital (RCH)
Royal Hobart Hospital (RHH)
Royal Prince Alfred Hospital (RPA)
St Vincents Health Network
Statewide Eating Disorder Service (SEDS)
Sunshine Coast Hospital and Health Service
Swinburne University of Technology
Sydney Children's Hospitals Network (SCHN)
Tasmanian Health Service (DHHS)
University of Sydney
University of Melbourne
Victorian & Tasmanian PHN Alliance (VTPHNA)
Victorian Centre of Excellence in Eating Disorders (CEED)
WA Country Health Service (WACHS)
WA Eating Disorders Outreach & Consultation Service (WAEDOCS)
WA Primary Health Alliance (WAPHA)
Western Australian Mental Health Commission
Western Sydney Local Health District
Western Sydney University
Western Sydney University Eating Disorders & Obesity Psychology Clinic
Womens & Childrens Hospital
Womens Health & Family Services