

Summary of National Consultations with People with a Lived Experience and Carers

NOVEMBER 2019

Thank you to everyone who gave up their time and participated in the recent person with a lived experience and carer national consultations. Yours is a vital contribution informing the development of the first National Research and Translation Strategy for Eating Disorders.

In March of 2019 InsideOut Institute began the development of a National Strategy for Research and Translation in Eating Disorders funded by the Federal government, commencing with nation-wide consultations in each state and territory.

The first round of consultations were collaborative and cross-sectoral; attended by people with a lived experience of an eating disorders and carer representatives, clinicians and service providers from both public and private services, academics and researchers, and representatives from state and national mental health commissions, state governments and the Commonwealth Department of Health.

In addition, four consultation meetings were held with people with a lived experience of an eating disorder and families and carers. These were promoted through consumer and carer organisations with broad geographical participation achieved through an online-consultation processes. Historically, eating disorders have had one of the lowest research dollar spends per affected individual. This lack of investment has had downstream effects on access to treatment and services, the type of care people with eating disorders and their carers receive, as well as recovery and outcome.

InsideOut's 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 will address prevention, early intervention and treatment of people with eating disorders.

This brief provides a summary of the key themes emerging from the consultations with people with a lived experience of an eating disorder and carers. It is not an exhaustive summary, it is a high-level synthesis of concepts that were repeatedly heard across all consumer and carer consultation meetings, using the words and voice of consumers and carers.

Where does 'the system' look to be uninformed by evidence?

Um, everywhere

So, what do we need to know?

Emerging Themes

Consumers and carers identified what the most important research questions are for them, what questions should be asked in order to ensure clinicians are more knowledgeable about the issues and services provided are better informed by evidence.

Research: Knowledge production

Prevention

Are eating disorders preventable, and if so, how?

In what ways are different food-related disorders (obesity, eating disorders) linked?

How does the health system take a more holistic and nuanced approach around nutritional communication so that public health messaging doesn't conflict?

Many people diet. What combination of factors tips someone into an eating disorder? How do we better promote these risks to help people to engage in behaviours that prevent eating disorders - in the same way we encourage people at risk of depression to be active, for example?

Other eating disorders are like the forgotten child. They can go undetected for so long. How do we make health care professionals more aware of a disease where someone looks like a normal person? How do we spread more awareness of this to the public? People think eating disorder and think anorexia. That's what we read about. So if you aren't skinny, you mustn't have an eating disorder.

Creating more general awareness would possibly increase detection and earlier intervention."

"Recent research was focused on the genes; the impact of that study made me think that I didn't really care about that. The fact that it was genetic didn't change how I perceived the eating disorder, or how I could get better...for me, research that focuses on the role of the socio-cultural context would be more interesting and also would give me some control... I can change that, I can't change my genetics"

Early Identification:

What key terms are coming up in GP consultations before an eating disorder diagnosis is made? What red flags might help a GP make an earlier diagnosis? How do we design a system or a tool that would automatically flag the idea that an eating disorder might be emerging?

How do we increase the research focus on the range of eating disorders?



Treatment

What works for who?

What treatments give a sense of relief from the disorder without eating being the only thing that is happening?

How do we identify the most effective mode of therapy for a particular individual? How can existing treatments be augmented and respond to individual needs?

Nobody actually gets better until they make a decision to recover & everybody's motivations for recovery are different...How can you encourage people to want to get better based on their own individual motivations and how can this be incorporated in to treatment?

What does the transdiagnostic journey look like? A lot of barriers are around awareness, because anorexia nervosa is known diagnostically and has been in the spotlight. There are severity labels, but we move between the diagnoses massively, so a trans diagnostic approach is required. How prevalent is this moving between diagnoses? What barriers does the 'downgrading' of a diagnosis put into people's way?

What is the impact of treatment?

What treatment-related trauma occurs? Are some treatments more traumatizing than others?

How can treatment-related trauma be minimized and addressed?

What is the impact on treatment when there isn't a full treatment team involved?

What behaviours are learned/created or increased during inpatient/outpatient treatment and does this affect outcome?

How do we move beyond the treatment experience?

How can we better support consumers and carers when someone leaves a treatment centre?

What treatments work for people who don't respond to existing treatments?

"When treatment doesn't work, this is a valuable opportunity to ask people why they dropped out. When I've dropped out of treatment, there is no researcher asking me what didn't work. People can be passionate about what didn't work for them – there's a whole group of people who treatment doesn't work for and getting more knowledge about that is important."

How can health break down the silo between medical and mental health to give better treatment?

How does peer mentoring work in eating disorders?

What happens when I'm not sick enough, too young or too old for treatment?

Recovery

Why are definitions of 'recovery' focused purely on physical parameters? This is only one part of treatment. What are the other markers of recovery? How do we measure change better?

How do we assess a person's state of recovery in such a way that it accurately reflects what's really going on? How do we ask the right questions about framing recovery?

What are the developmental delays that occur during illness? And what adjunctive therapy and life-based treatment and support is required to overcome these delays for a full recovery?

"In cancer treatment, you attack the cancer, not the symptoms of cancer. If we just treated cancer by treating the symptoms of nausea and exhaustion rather than treating the cancer, we'd all die of cancer."

Translation: Knowledge Production

“There’s a recurring theme of health care professionals who are not well informed... particularly GPs and Emergency Departments, but also inpatient units and eating disorder services. When I looked for validation from health care professionals, if I ‘looked’ OK, I didn’t receive the help I need. This is a block at the front door... If people don’t take it seriously, it can throw you off in numerous different directions. Being shunned away makes people worse”

Early Identification

What are the causes and the (early) behaviours/ symptoms and how is this information best translated to the right clinicians in order that people at risk are recognised and acted upon early?

Are all clinicians appropriately trained to provide the services they need to?

What knowledge and skills do different health professionals require?

How do we deliver that knowledge in such a way that it is applied in practice?

Are parents and carers getting the support that they need to provide treatment?

“Lack of understanding created problems for me in my rural town. I had to drive an hour and a half to get treatment and I was denied treatment consistently. I had to move to a main town – 16 hours from my home. That was great for me because my parents had the money; but what if they don’t? Can treatments be delivered in other ways?”

“Every single person your child comes across in treatment must know what the symptoms are, what does and doesn’t cause it, what happens in the brain, about the evidence base, that parents don’t cause it and that refeeding happens first... No-one should be allowed near our children until they can prove they know those things... otherwise they put our children in danger.”

“Our experience was that practitioners were often dismissive of the risk of suicide and even our daughter’s close but unsuccessful attempts had little impact on the treatment she received, and the support given to us as a family..... At the local level eating disorders are not seen as being a significant risk factor which needs to be addressed.”



Implementation: Knowledge Production

“All the books talk about the multi disciplinary team – and I say, where are those specialist talking together and working in concert for the betterment of the patient?

There’s certainly none in my area!”

What happens with treatments in the real world? Is the evidence and knowledge being used where it needs to be used?

What is the difference in access to treatment and outcome for people in regional, rural and remote areas?

There are pockets of really good practice happening in Australia – Why do we have these good and bad pockets? How do we make good treatment happen everywhere? Is it that some places are following the evidence base and others aren’t?

How do we support carers whose loved one refuses to access formal treatment? What skills do carers need under these circumstances? How can health services support this to happen?

How do we build a peer workforce and where will it fit?

What is the impact of a peer workforce and lived experience leadership on the culture of eating disorder service delivery?

How do we improve the person’s experience at transition points we know are difficult?

What can be learned from people who do not recover, or who don’t fit in with the existing treatments? And how should our services respond to this knowledge?

“...Why are hospitals turning people away when they ‘aren’t sick enough’, or they don’t do what they are ‘supposed’ to do? My daughter is not eating because that’s a symptom of her disorder...do you turn cancer patients away saying they’re not at stage 4 yet? do you cut out the cancer but then not treat them with chemo?”

“What is the impact of moving evidence based treatment from research facilities and randomised controlled trials into the real world? I would’ve been excluded from every RCT ever done. What’s missing and what changes in community based practice? And, what would help evidence based practice to sit in private practice better?”





The role of consumers and carers of people with a lived experience in research...

Everyone's experience is useful from across the disorders and across the wellness-illness spectrum. The consumer voice, of someone who has recovered, is vital, but people who are unwell should also be involved. Not everyone can contribute in the same way, nor do they want to. If it's carer research, a carer should be in charge... or co lead, co-design with carer and consumer. Consumers and carers can ensure the questions are asked sensitively and not do harm.

Let us in to the extent that we can participate; partner with us; co-design with us; cooperate with us.

One carer or consumer on the team isn't enough to get the carer or consumer perspective; we need a wide range of people involved to get the breadth of experience.

Being a researcher with a lived experience is valid for conducting research in this field and does not necessarily lead to a bias on the part of the researcher.

"Only people with a lived experience can provide a certain level of insight into the experience. It's a dark insight... I understand more and more what was/is going on and have more to contribute as I go along."

What would help you to become more involved in research?

Just ask us

Teach us what you need us to be able to do, so we can make a meaningful and beneficial contribution. Make research accessible for us to participate in. Early adopters are already involved and are influencing research. To grow the conversation, show more people talking about eating disorders, standing up and getting involved in the discussion. Diffuse the stigma, then you've got access to a massive pool of people willing to contribute.

Ask consumers and carers what they wished they would've known, what would've been helpful and how they could've been better supported in their experience.

Establish a Consumer and Carer Research Advisory Committee. Require that all eating disorder research be passed through this committee and supported by it, before Ethics submission.

Ensure that all research projects include consumers and carers. Nothing about us, without us.

"Often people with eating disorders are passionate, empathetic people who would really like to share their stories and help other people. We just need the right forum to get it out there which will attract people more and more. Not everyone will want to get involved with research, but they might want to help just one other person, so providing options for how they could do that would be great."

Thank you to all involved in the consumer and carer consultations...

**The consumer and carer voice challenges us to
conduct research that matters, that answers questions
that will make a difference to your lives and that will
transform your experience of the health care journey.**

**We thank you for your time, your passion and the
generous way you have thought about and shared
your experience with us...**