

# INSIGHTS IN RECOVERY

An overview of the research project informing the *Insights in Recovery Guide* for practitioners working with people with eating disorders

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An overview of the research project informing the *Insights in Recovery Guide* for practitioners working with people with eating disorders



**Mental  
Health  
Commission**  
of New South Wales



**Butterfly**  
Foundation for Eating Disorders

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## ABSTRACT

Eating disorders are serious mental health conditions associated with significant physical complications. Insights in Recovery was a consumer participatory research project translating knowledge from lived experience into a framework of recovery oriented practice for health professionals working with people with eating disorders.

The personal approach to recovery is now central to mental health care policy and standards in Australia. There is very little in the literature on the usefulness of the personal approach to recovery for people with eating disorders, however; some authors (for example; Dawson, Rhodes & Touyz, 2014) have proposed that the personal recovery model could be beneficial to people with eating disorders.

The substantive component of the project involved extensive consultation with consumers. 104 participants shared their narratives of recovery through an online survey. Thirteen participants contributed through focus groups with a proportion of participants completing both. The majority of participants were female (95%). All eating disorder diagnoses were represented in the sample; the majority had experienced anorexia nervosa (72%) at some time.

Important issues for participants included developing a sense of identity, experiencing personal agency in recovery, supportive relationships, choice and a sense of control, confidence and hope. Participants wanted to be seen as an individual person first rather than feeling categorised by their illness.

Recovery was understood by participants to be a process of regaining a satisfactory life that was no longer dominated by thoughts of food or the punitive eating disorder voice. The narratives strongly emphasised the persistence of eating disorder thoughts after treatment and the need for access to on-going help to learn to manage these thoughts. Of note was the emphasis on gaining early access to eating disorders treatment, and treatment for the fatigue and physical consequences of eating disorders as factors contributing to social inclusion.

A disconnect in communication between health professionals and people with eating disorders was noted with significant impact on motivation for recovery in the early stages of help seeking. Feeling understood, safe and valued in treatment settings emerged as strong themes.

Overall, the data collected in the Insights in Recovery project supports the use of the personal recovery model as relevant to people with eating disorders. This project has highlighted areas where recovery oriented approaches for people with eating disorders may require a different emphasis.

Findings from this study have informed the development of a new resource on recovery oriented practice as a companion to the National Framework for Recovery Oriented Mental Health Services (2013): *Insights in Recovery: A consumer-informed guide for practitioners working with people with eating disorders*.

The Insights in Recovery project was implemented by the Butterfly Foundation in partnership with the Mental Health Commission of NSW, and supported in part by the Ian Potter Foundation.

# 1. INTRODUCTION

The Insights in Recovery project explored recovery oriented healthcare practices that are meaningful for people with all eating disorder diagnoses.

Full recovery, defined as no longer meeting diagnostic criteria for an eating disorder and achievement of a personally satisfying quality of life, is possible (Bardone-Cone et al., 2010). As such, recovery should always be the goal of treatment, defined in ways that are meaningful to both the person and their treatment team (NEDC, 2012). Gaining insight into consumer experience of recovery is essential for effective implementation of mental health recovery policy. Exploring what motivates people to engage in the work of recovery and how they understand recovery in their lives may usefully contribute to the development of effective practice.

Theories of recovery have largely emerged from the experiences of consumers with psychosis (Jacobson & Greenley, 2001; McCranie, 2011; Morrow & Weisser, 2012). In applying personal recovery concepts to people with eating disorders it is essential that we identify whether these concepts can validly be generalised to this population and what the implications are for practice.

The National Framework for Recovery-Oriented Mental Health Services (Department of Health, 2013) is founded on an understanding of recovery as a personal process. Although there is very little in the literature on the usefulness of the personal approach to recovery for people with eating disorders, some authors (for example; Dawson, Rhodes & Touyz, 2014) have proposed that the personal recovery model could be beneficial to people with eating disorders, particularly for people with longer experience of illness.

Limited evidence presents a challenge to the promotion of recovery approaches for eating disorders. In applying personal recovery concepts to people with eating disorders it is essential that we identify the implications for practice. There is a need to more clearly define recovery and the strategies that lead to recovery for people with eating disorders. In some areas the needs of people with eating disorders are likely to be different to those of people with other mental illnesses.

The consumer voice is fundamental to our understanding of what contributes to personal recovery as in this field the person, rather than the diagnosis, should be the focus for practical mental health care (Kogstad et al., 2011).

The Insights in Recovery project took as its starting place the National Framework for Recovery-Oriented Mental Health Services (Department of Health, 2013), focusing on the relevance and practical implementation of recovery principles for people with eating disorders.

As a project developed in partnership with the Mental Health Commission of NSW, the Insights in Recovery project actively sought to be aligned to implementation of Living Well: A Strategic Plan for Mental Health in NSW 2014 – 2024 and the NSW Service Plan for People with Eating Disorders (2013).

## 2. BACKGROUND

### 2.1 Eating Disorders

Eating disorders are serious mental illnesses which are associated with significant physical complications. This group of psychiatric illnesses includes anorexia nervosa, bulimia nervosa, binge eating disorder, and 'other specified feeding and eating disorders' (APA, 2013).

People with eating disorders have disturbed eating behaviours and distorted beliefs, with extreme concerns about weight, shape, eating and body image. These disorders have been shown to have one of the highest impacts on health related quality of life of all psychiatric disorders (AIHW, 2008).

All eating disorders carry the risk of severe medical complications and increased mortality rates. Eating disorders may result in significant physical complications and impairment including chronic heart and kidney disease, osteoporosis and

diabetes. The consequences of an eating disorder are not limited to acute episodes of illness but may also be long term, and chronic physical complications can occur early in the course of illness (Katzman, 2005).

Eating disorders have the highest mortality rate of all psychiatric illnesses; some studies show up to 20% (Arcelus et al., 2011).

The risk of premature death in people with eating disorders relates in part to medical complications, however; suicide has also been identified as a major cause of death in people with eating disorders. One in five individuals with anorexia nervosa who die prematurely die by suicide (Arcelus et al., 2011). Research on suicide in people with other eating disorders is less available; however rates of suicide in bulimia nervosa and binge eating disorder are higher than in the general population (Wade et al., 2015).

Eating disorders have a significant and underestimated impact on Australian society. At any point in time, about one in 20 Australians has an eating disorder and this rate is increasing (Hay et al., 2008). Approximately 15% of Australian women experience an eating disorder during their lifetime (Wade et al., 2006).

## 2.2 Recovery from an Eating Disorder

Approximately 50% of people clinically recover from their eating disorder, demonstrated by an absence of symptoms (NEDC, 2012), taking an average seven years to achieve full recovery (Strober, Freeman & Morrell, 1997; Wade et al., 2006). A recent study found that 44% of people who had received treatment for eating disorders still met the diagnostic criteria for an eating disorder ten years later (Lannfelt et al., 2014). Relapse and recurrence are significant issues, with rates of relapse ranging from 22% to 51% across studies of people with anorexia nervosa and bulimia nervosa (Keel et al., 2005).

Recovery from anorexia nervosa has been described as a complex process with no single 'correct' pathway (Hay & Cho, 2013); a process that requires much more than clinical treatment (Espindola & Blay, 2009). Similarly, studies of recovery from bulimia nervosa indicate that recovery is a 'long journey that involves both setbacks and forward motion' (Reynen, 2012).

Recovery-oriented approaches in treatment aim to support individuals in taking responsibility for their personal journey to recovery and offer a collaborative holistic framework to work within.

Person-centred care, tailored to suit that person's illness, situation and needs, is the most effective way to treat someone with an eating disorder (Hay et al., 2014). Understanding recovery from the patient's perspective helps to understand and tailor patient centred care and improve patient outcomes.

Although therapy for eating disorders is crucial to recovery, people with eating disorders identify a much wider range of factors that contribute to personal recovery including personal relationships, meaningful activities and positive life experiences (Espindola & Blay, 2009; Hay & Cho, 2013; Reynen, 2012).

Personal recovery means building a better future founded on whatever the person's present circumstances may be. With this approach every experience of recovery starts from a different place and leads to a different (personally defined) concept of recovery (Dawson, Rhodes & Touyz, 2014); there is no standard or universal goal to be achieved.

If recovery is a choice to pursue a personally defined vision of a better quality of life, then it is also a choice that must be made repeatedly throughout the recovery process. Set-backs and relapse are considered to be a common part of the process of recovery and not major obstacles to recovery (Reynen, 2012).

Although there is very little in the literature on the usefulness of the personal approach to recovery for people with eating disorders, some authors (for example; Dawson, Rhodes & Touyz, 2014) have proposed that the personal recovery model could be beneficial to people with eating disorders, particularly for people with longer experience of illness.

From the perspective of people who have experienced an eating disorder, research has identified five factors that are important manifestations of recovery: having self-acceptance, accepting one's body, having a relaxed attitude to food, having a functioning social life, and being in contact with and having the courage to express emotions (Björk & Ahlström, 2008).



While wholly personal definitions of recovery are scarce in the eating disorders literature, the studies referred to in the section below generally investigated the ability of individuals to sustain clinical recovery after treatment which, while not defined as such, certainly overlaps with personal recovery. They concluded the following aspects were important to recovery from an eating disorder.

### **Connection**

Making new social connections and building satisfactory relationships with others.

This is the most commonly identified factor supporting recovery for people with eating disorders (for example; Espindola & Blay, 2009; Federici & Kaplan, 2008; Hay & Cho, 2013). Connections are desired with others who have experience of an eating disorder, and family and friends (Hay & Cho, 2013; Reynen, 2012). Lack of social support and feeling misunderstood contributes to feelings of isolation and frustration (Federici & Kaplan, 2008) which can be barriers to recovery.

### **Motivation**

A personal desire for recovery and the belief that this is achievable, expressed as a self-directed decision to recover.

This has most commonly been identified by people with anorexia nervosa (Dawson et al., 2014; Federici & Kaplan, 2008; Hay & Cho, 2013) and bulimia nervosa (Reynen, 2012) as an important step towards sustained recovery. People with eating disorders identify themselves as the active force in their own recovery (Nilsson & Hagglof, 2006).

### **Interests**

Life activities, hobbies and interests beyond illness, study and work (Hay & Cho, 2013).

People who actively develop activities and relationships that broaden their life horizons rather than focusing on their illness are generally better able to sustain recovery (Björk & Ahlström, 2008).

### **Expressing Emotion**

The ability to sense and manage emotions.

Self-acceptance and the ability to express emotions are two of the factors that have been found to be indicators of recovery from eating disorders (Björk & Ahlström, 2008). Continuing to practice recognising and managing emotions after treatment has finished contributes to sustained recovery. Practice that involves communicating with others helps to increase self-esteem and enable healthy expression of emotions (Federici & Kaplan, 2008).

### **Knowledge of Recovery**

An understanding of recovery as an on-going process that requires sustained effort.

People who understand treatment as a first step in recovery rather than the full process and who have realistic expectations of life in recovery are more likely to sustain their recovery than those who do not anticipate the challenges ahead of them (Federici & Kaplan, 2008). Understanding recovery as a long process rather than a 'quick fix' is an important part of the recovery process (Reynen, 2012).

## **3. METHODOLOGY**

This was a co-designed and co-managed research project involving shared leadership between specialists in eating disorders and people with lived experience. The substantive component of the project involved extensive consultation with consumers.

The aim of the project was to establish a consensus guide to the provision of recovery oriented services for adults with eating disorders that are experienced as motivating, hope inspiring and empowering for sustained recovery.

The project adopted a participatory approach involving people with lived experience in the design and management of the

project as well as being subjects of consultation. Participatory research methods must be informed by, and emerge from, engagement with consumers in response to their issues and needs. An Expert Advisory Group was appointed including consumer researchers, qualitative researchers and experts in the clinical treatment of eating disorders to ensure that the project was truly participatory in nature. This group had responsibility for oversight of every stage of the project.

The project commenced with a review of the National Framework for Recovery-Oriented Mental Health Services from an eating disorders perspective and identification of specific issues for further investigation. A wider review of the literature was conducted to provide a frame of reference for interpreting consumer narrative data.

Multiple consultation methods were used to ensure that as many people with lived experience as possible had an opportunity to participate at a level which was safe and appropriate for their stage of recovery.

The stepped and iterative approach was developed by the National Eating Disorders Collaboration and has been used effectively since 2009 to engage with consumers, carers and clinicians. Details of the consultation process are included in section 3.1.

### 3.1 Consultation Process

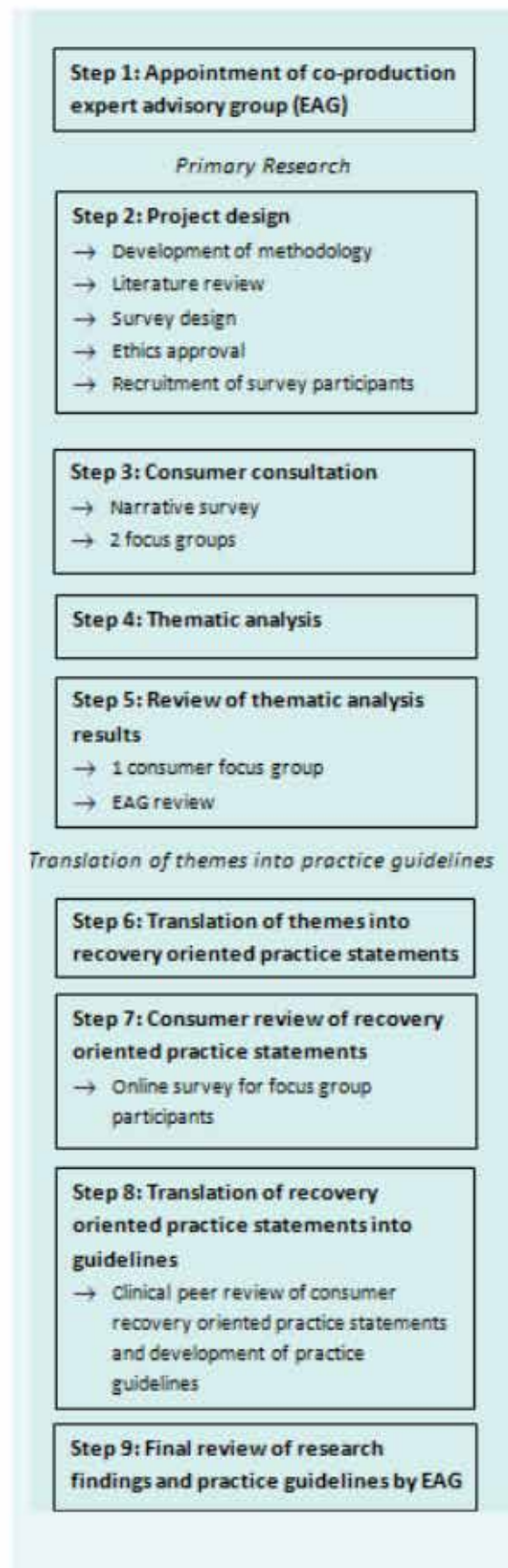
The consultation process was based on the Delphi approach to consensus building (see Sumison, 1998 and Hsu & Sandford, 2007 for a detailed description), having three rounds of consultation. Consultation methods included, in order:

#### 3.1.1: Questions to gain a broad understanding of the individual experience of recovery

##### Online narrative survey

Online surveys provide a low risk, easily accessible path for participation. Online surveys are a standard method used to gather information and achieve a consensus in many studies of a similar nature to this project (Byrne & Morrison, 2014; Dawson, Rhodes & Touyz, 2015; Lakeman, 2010; Mittnacht & Bulik, 2015; Reavley et al., 2012).

While called a survey, the online tool primarily provided an opportunity for people to share their experience of recovery as a narrative in their own words. The survey was promoted through the Butterfly Foundation's extensive consumer network and through social media.



### 3.1.2: Questions to delve deeper into the recovery topics

#### Focus groups

Two focus groups were conducted, one in Sydney and one in Melbourne. The groups were run concurrently to the delivery of the initial survey. Each focus group was run as a single, independent session. Group size was intentionally small reflecting the sensitive subject matter and the need to provide peer support as part of the group process (Tynan & Drayton, 2007).

The groups provided an opportunity for participants to share experiences, give and receive support and encouragement, and learn from other members what has been helpful for them on their recovery journey thus contributing directly to their wellbeing. The groups were facilitated by a professional facilitator and a peer support worker.

The focal question posed was: What helps people to recover from an eating disorder? A series of open ended conversation starters (For example; recovery is... what does recovery mean to you?) were used to initiate discussion.

#### Review group

A further focus group was conducted in Sydney after the initial thematic analysis of survey and focus group data. These groups reviewed the initial results and compared these with their own experiences and expectations. The groups were designed to gather information to inform the thematic analysis and contribute to consensus building.

### 3.1.3: Questions focussed on establishing priorities amongst the emerging themes

#### Online survey

A final anonymous online survey was used to enable participants from the focus groups and survey to indicate the relative importance of the identified themes.

## 3.2 Translating Narrative into Professional Guidance

An evidence-based approach has been used to inform the development of the Insights in Recovery Guide. Themes identified in the analysis of consumer feedback were mapped to common recovery themes evident in the current recovery literature (Australian Health Ministers' Advisory Council, 2013) in order to identify areas in which guidance specific to recovery oriented practice for people with eating disorders were required.

These thematically grouped statements were then compiled into a narrative recovery story. Multiple voices were combined into one overarching story with a temporal ordering of events to create a meaningful whole reflective of the experience of recovery from eating disorders (Sakalys, 2003).

An evidence-based approach was used to inform the language used to present evidence and develop key points for practice in the *Insights in Recovery Guide*:

- person-centred language was deliberately used to model a recovery mindset (Australian Health Ministers' Advisory Council, 2013)
- suggested recovery oriented practices were framed as learning rather than performance goals. Learning goals are less threatening, induce less anxiety and induce enhanced intrinsic motivation than performance goals (Grant, 2012)
- use of the word "can" models provision of choice and autonomous action that promotes internal motivation rather than controlled external motivation implied by language such as "must" or "should" (Deci & Ryan, 2008)
- imperative verbs were used to create clear calls to action as a form of goal priming and are designed to help clinicians set goal intentions about their future behaviour (Gollwitzer, 1999; Laham & Kashima, 2012).

## 4. RESULTS; PRIMARY RESEARCH

One hundred and four (104) individuals responded to the first round of consultation in the narrative online survey. Thirteen people participated in one of the two focus groups (10 completed both survey and focus group).

The open narrative form of the survey (refer to Appendix B) meant that participants were able to choose how many questions they answered and how they responded to them. The number of people who responded in each field of inquiry does not therefore necessarily represent all 104 participants. When interpreting results it is also important to note that respondents were able to reflect multiple experiences and opinions and this may be reflected in the percentages noted.

### 4.1 Demographics

A significant majority (95%) of respondents identified as female. 90% of cases of anorexia nervosa (AN) and bulimia nervosa (BN) occur in females (NEDC, 2012).

Participants were most commonly aged between 18 and 28 (46.2%). A further 30.8% were aged between 29 and 38. 18.3% were aged between 39 and 58.

Many experienced different diagnoses at different stages in their lives (30%). The majority experienced anorexia nervosa (72%), then bulimia nervosa (26%), other specified feeding and eating disorders (OSFED) (22%) and binge eating disorder (6%). Eating disorders can be considered to exist within a spectrum, with between 10% and 30% of people crossing over between anorexic and bulimic tendencies during the course of their illness (NEDC, 2012).

10% of respondents had self-diagnosed their condition and had not received a clinical diagnosis of an eating disorder. All responses were included in the analysis of the results. There was no discernible difference in responses based on diagnosis and the Insights in Recovery Guide therefore refers to the whole group of eating disorders.

People from every state and territory participated in the survey. More than one third of respondents lived in New South Wales across both metropolitan and regional areas. Participation from areas other than New South Wales generally reflected the distribution of the Australian population with slightly higher representation in Victoria (27%), Northern Territory (2%) and Australia Capital Territory (2%) than may have been expected. Some respondents did not indicate whether they lived in a rural or metropolitan location. Where this information was provided, 18.5% of respondents indicated they lived in a regional area of Australia.

The narrative responses give a good indication of individual experiences of eating disorders. Many described their time from prior to diagnosis to recovery; describing childhood behaviours and patterns as well as ongoing struggles with eating disorder thoughts or feelings, or other subsequent mental health issues.

Some participants did not define the age they were at the onset of their eating disorder, but when it was noted, the ages 14 – 16 seems to have been the most common experience.

### 4.2 Concepts of Recovery

Participants defined recovery in terms of individual growth and learning, working towards personally defined and meaningful life goals.

*“Recovery is unique to the individual and is ongoing.”*

*“Learning strategies to control your thoughts.”*

*“Working towards your own life goals...”*

*“Resolution of the underlying issues that started the eating disorder, not just stopping the behaviours.”*

*“Regaining a fulfilling life. Recovery is like who you are. Not just your body but who you really are as a person.”*

*“It’s not simply going back to what life was like before. It’s growing and learning and reaching a better place.”*

There appeared to be a disconnect, between the respondents’ understanding of recovery and the messages they had received from their healthcare professionals. Recovery from the respondents’ perspective was not solely about the diagnostic criteria of weight and eating behaviours. The focus of their attention was on ongoing eating disorder thoughts and regaining quality of life.

Focus group participants questioned whether they were ‘recovered’. While living an improved quality of life, and in many instances no longer meeting diagnostic criteria for an eating disorder, participants noted the on-going presence of eating disorder thoughts.

“I began my struggle with Anorexia Nervosa when I was 15 years old around 2009. I still struggle today with my disorder thoughts but [am] in a much better place with finding myself”

*“You get the impression that recovery is all behaviour based. [That] it’s all about weight and eating not about the thoughts, but this isn’t real.”*

*“It’s not just weight and food – this is not helpful for recovery.”*

*“Are you still recovered if you have some [eating disorder] thoughts? I expected it all to be gone and it’s not.”*

### 4.3 Types of Treatment Accessed

Participants were asked to “List all the different treatments you have accessed throughout your journey of recovery” (Survey Question 7). 57 of the 104 (55%) respondents answered the question on type of treatment, indicating that they had accessed treatment for their disorder. Percentages below relate to the proportion of the 57 people who answered the question.

People with eating disorders may receive treatment from a wide variety of medical and mental health professionals and allied health professionals. Most respondents listed multiple types of treatment, often engaged sequentially but also engaged simultaneously. Where types of treatment were listed:

- 77.2% accessed a psychologist
- 49.1% accessed inpatient treatment (either general, eating disorders specific, or both)
- 38.6% accessed a psychiatrist
- 33.3% accessed a dietitian and/or nutritionist
- 33.3% accessed a counsellor and/or psychotherapist
- 31.6% accessed a GP specifically for their eating disorder.

Some respondents had accessed specialist eating disorder services:

- 21.2% accessed a specific eating disorders day program
- 14% accessed an eating disorders specific outpatient program
- 5.3% accessed eating disorder specific residential services (usually specified as in the USA).

Narrative on the experience of treatment specifically received for the eating disorder provided a very mixed picture. While some noted positive experiences, many respondents noted that the treatments they attempted were not successful for

them, while others gave no assessment of the treatments.

It was quite common for respondents to have accessed allied and complimentary health services. While some indicated that these enhanced their wellbeing in conjunction with eating disorder specific treatment, others noted these treatments as their primary or most effective intervention. The range of non-eating disorder specific treatments accessed included:

- 21.1% accessed complimentary treatments (For example; naturopaths, acupuncturists, homeopaths)
- 8.8% accessed recovery support (For example; peer support groups)
- 8.8% accessed Telehealth and/or Helplines (For example; Butterfly, Kids Helpline, Reachout)
- 7% accessed self-help (For example; books, own personal reflection)
- 7% accessed yoga or other meditation practices
- 7% accessed other therapists (For example; art, hypnotherapy)
- 7% accessed physical therapies (For example; massage, chiropractic)
- 5.3% accessed other medical professionals (For example; endocrinologist, sports medicine)
- 3.5% accessed life coaches or other professional motivational support.

## 4.4 Thoughts and Feelings

Participants were asked to “describe your experience in seeking help for your eating disorder” (Survey Question 8) including describing the thoughts and feelings that accompanied different events.

54 of 104 participants responded (52%) to the question on thoughts and feelings. The emerging themes in these narratives were fear, shame, guilt, hopelessness and ambivalence.

*“Absolute fear invaded every area of my life. I had to be perfect to be accepted. Fear of aging. Fear of what people would think and say.”*

*“Fear that I wouldn’t get better, fear over getting fat or losing control, over what I would eat and how many calories were in each morsel. Fear that people would find out, that I wouldn’t ever be enough. The fear was exacerbated by the panic.”*

*“Shame was the biggest. I felt I couldn’t seek help because it was stupid and cheating to lose weight”.*

*“The most important feeling I felt during my eating disorder was guilt. I felt terribly guilty for putting my family through this, for seeing how upset it made my family. I constantly felt guilty for lying...”.*

*“With each treatment failure, there is a greater sense of hopelessness. Particularly in relation to the holistic health retreat - after which I also felt like a desperate fool”.*

Narratives illustrated respondents’ often conflicting thoughts and feelings about recovery.

Some of these promoted engagement in recovery. For example; “If I’m going to be suffering either way, may as well make it TOWARDS something” and “I may as well go through a few months of recovery - which will also be hell - for a shot at something better”. Others describe feelings of deep misery. For example; “I’m in hell”. “Feeling like a bird inside of a cage”. “Not feeling good enough”. “Losing the appetite for living”. “Deep sadness”. “Anger”. “Anxiety”. “Small”.

*“I remember having mixed emotions. I was sort of happy that I hadn’t put on the required weight, but disappointed with myself because I knew that my partner and family would be disappointed that I wasn’t ‘thriving.’”*

## 4.5 Helpful Treatment Approaches

Participants were asked to describe the most helpful (Survey Question 9) and least helpful (Survey Question 10) aspects of their recovery journey.

47 respondents answered the two questions relating to this topic (45.2%). Several respondents (13%) specifically and only indicated that they did not find anything about their experience helpful and/or that they didn't access a formal type of treatment/process. For example:

*"I haven't had any positive experiences when it comes to treatment settings".*

*"Most organisations especially hospitals and mental health organisations that didn't understand mental health did more harm than good".*

*"I sadly never came into contact with a doctor or counsellor who could get through to me. I always felt attacked and vulnerable".*

The respondents who identified helpful aspects spoke of the relationship with the therapist, the delivery of therapy, and the service setting.

### 4.5.1 Therapeutic Relationships

Qualities appreciated in the therapist focussed on human interaction, professional skills, knowledge about eating disorders and attitudes towards recovery.

Honesty, caring, compassion, calmness, understanding and being non-judgemental were frequently recurring descriptors of helpful therapeutic relationships. A sense of humour was also mentioned as an asset in healthcare staff. Where these qualities were not perceived in the health professional there was a belief that treatment could not be effective.

*"You can't 'treat' a person when you don't listen or show respect for them as people".*

*"I needed people who were gentle with me and nurtured me".*

*"If people can't relate to who you are as a whole person, what happens to your identity? I don't think that everyone gets how low your self-esteem goes. If people didn't pay attention to what I had to say and who I am then I would take it on board that I wasn't interesting enough".*

Trust was a recurrent theme associated with relationships in which the person felt able to express themselves safely. For example; "They established trust and allowed me to voice previously silent concerns."

Establishing clear professional boundaries was also identified as helpful. For example; "Health professionals who were empathic but firm and clear about the things I needed to do to get well assisted me most".

The health professional's knowledge about eating disorders was identified as a key to helpful treatment. For example;

*"Professionals who were well trained and knew what they were doing".*

*"Professionals who were NOT working directly out of the outdated eating disorders section of a text book".*

*"Specialists with more understanding into the head stuff and less authoritarian approaches".*

*"The treatment provider needed to respect that not all ED patients are the same, we are not all driven by social pressure and it is such a multifaceted disease".*



However, this was counter balanced by the narratives of people who had experienced a learning partnership with their health professional. Learning together about eating disorders was regarded as a positive experience.

*“The most helpful clinician I ever had wasn’t an expert in ED. He said ‘I know nothing about ED so you will have to help me out’. He was completely open.”*

*“Professionals need to meet us half way so we can work this out together. They don’t need to have all the answers”.*

Belief in recovery regardless of the person’s circumstances and a realistic understanding of the process of recovery was identified as motivational. For example;

*“...The staff had energy about recovery and telling the truth. They also employed recovered staff so that helped to have role models to aspire to”.*

*“Worked more on realistic, strategic, small steps...which overall benefited me... The steps for RECOVERY were small steps - fitting in & then adjusting along the way... learning that if I go backwards it doesn’t mean I can’t move forward”.*

#### 4.5.2 Delivery of Treatment

A key theme in narratives about treatment was that this should not be focused on the body and food. For example;

*“There needs to be less focus on food and weight gain and more on the head stuff that doesn’t go away just because someone has been able to re-establish a better eating plan.”*

Having choice and a sense of autonomy were also strong themes associated with helpful practice. For example;

*“A setting where I was encouraged to assume responsibility for my recovery and was given clear boundaries/guidance on what constituted ‘recovery’ and appropriate behaviour was helpful.”*

Many participants referenced the type of psychological therapy or other treatment that their professionals delivered as being helpful; however, there did not appear to be a consistent pattern of which treatment was most helpful. The treatments noted included but were not limited to; Cognitive Behavioural Therapy, Dialectical Behavioural Therapy, Maudsley Family Based Therapy, hypnotherapy, pharmacological intervention, tapping therapy, and naturopathy.

#### 4.5.3 Service Setting

Several respondents (24%) made some reference to aspects of the general system of eating disorders treatment or mental health treatment. While these were often unique to the experience of the individual some repeated comments related to: affordability, the need for access to a wider range of services, and the need for access to tele-health services outside usual business hours. Specific reference was made to the following themes.

##### **Access to and duration of treatment**

Respondents described a need for longer programs of treatment and access to help outside routine service hours. Particular mention was made of the need to sustain treatment rather than discontinuing treatment before eating disorder thoughts had been sufficiently addressed.

*“By far though the most helpful was having someone ‘on call’ pretty much 24/7 to help me work through emotional crises and moments of distress”.*

*“Didn’t give up on me or discontinue treatment prematurely”.*

*“Longer admissions instead of the two weeks only which to me accomplishes nothing and is not helpful.”*



### **Integrated multi-disciplinary team treatment**

The value of coordinated care was highlighted in respondents' narratives. For example;

*"My GP putting together a management plan and staying in contact with the other professionals who were also looking after me".*

*"...All kept in contact with me and with one another, and we're all on the same page in terms of my illness and my recovery".*

*"There needs to be the same small support team so that a trust can be established..."*

### **Skills based learning and therapy**

Eating disorder treatment programs that incorporate skill development were identified as helpful, particularly those with an emphasis on food related skills, planning and stress management skills. For example;

*"I initially felt so stupid not knowing how to plan meals or shop or store food but when I voiced it in therapy the other clients were a great support".*

*"Planning is key for my recovery. 'This is practice for when I get home'".*

### **Community based residential support programs**

Older participants with experience of a long course of illness identified the need for support and respite rather than hospitalisation. For example;

*"Over time when you get older and have struggled for a very long time you basically need help to support you in life without the trauma associated with yet another inpatient stint".*

*"A residential setting would be ideal to establish which doesn't exist in Australia but this needs to be for those who have struggled for 30 years or more and are in the older age bracket".*

## **4.6 Peer Support**

Overall general narrative responses did not include references to peer support. When asked specifically about peer support in survey questions and in focus groups, 70% of the people who responded did have contact with a recovered person during their recovery although in most instances this was informal development of peer friendships rather than formal peer support. Specific reference to peer support was included in the survey questions to prompt responses on this topic. Peer support was identified as a part of treatment processes by less than 10% of respondents, possibly due to the respondents' limited access to formal peer support.

When asked how peer contact had been useful in their recovery, the themes that arose included:

- hope and motivation
- belief that recovery is possible
- realistic picture of recovery and validation of own experience
- learning practical coping skills and strategies
- general social connection - feeling less alone.

Respondents also identified potential negative consequences such as learning negative behaviour patterns from others. Focus group discussion concluded that there was a need to carefully match peers to ensure an appropriate peer relationship.

## 4.7 Recovery Orientated Practice Statements

Participants were asked to respond to a number of statements which were based on research evidence regarding factors that support recovery from eating disorders:

*“Which of the following ten aspects of recovery-oriented treatment would you say are important in the treatment of eating disorders and which of the following statements can you relate to in the context of your personal recovery experience?” (Survey Question 11).*

Responses to these statements are detailed below.

### 4.7.1 ‘Professionals communicated positive expectations, hope and optimism’

This was seen as important for the majority of respondents, many of whom indicated that they had had a negative experience in not receiving this from the professionals involved in their care.

Positive themes that arose for the statement on professional communication included:

- the importance of listening to the client and their family
- recognition of the individuality of illness *“Lived experience is often different to education/theory, awareness that one size doesn't fit all and all deserve optimism”*
- how the communication of belief in recovery can instil hope *“important to have from a clinician when you don't have it in yourself”.*

### 4.7.2 ‘Professionals made me feel valued, important, safe and welcome’

‘Valued’ was the word most commonly reflected in the responses from participants. To perceive that they were valued, participants looked for trust, non-judgemental responses, and respect for their individuality. Some participants noted that when they did not feel valued it decreased their engagement with treatment.

*“Being valued and welcome in an eating disorder context means professionals accepting of individuals' values without engaging with the eating disorder self”.*

### 4.7.3 ‘The treatment I received was holistic and person-centred, meaning that I was put first and was at the centre of the care I received’

Respondents noted that individual centred approaches increased their satisfaction and engagement with treatment. They also noted that calling a program ‘person centred’ did not ensure that the treatment was actually flexible enough to meet individual need. Respondents had different experiences of person-centred care in different settings.

Responses to the statement on person centred care indicated very variable experience in treatment. Respondents identified practices such as being empowered to make choices, support for their identity, and personal goal setting as desirable aspects of holistic person centred approaches.

### 4.7.4 ‘I felt motivated by a personal desire to recover and a belief that this was achievable. I took personal responsibility for my recovery.’

A majority of respondents were consistent in their expressed desire to recover and some noted that this motivation to achieve recovery was essential regardless of what treatment was received. However, some noted that motivation potentially becomes more important later in the recovery journey. In the early stages physical ill health can be a barrier to motivation.

Some respondents also noted that motivation could be external, related to someone the respondent cared about more than to their own internal motivation. For example; *"I can disappoint myself but I can't disappoint them [those who support me]"*.

#### **4.7.5 'Focusing on my strengths and working on developing activities, hobbies, interests and social relationships outside of my eating disorder were important factors in my recovery'**

Respondents consistently agreed that this was important. Narrative responses included feeling connected to the world and feeling that they had value and an identity separate from the eating disorder. A connection was made between improving their range of life activities and improvement in their mental health. For example;

*"Rebuild myself from the ground up".*

*"If the rest of my life improved so would my eating disorder".*

Some respondents noted that it can take time to develop and move towards activities and that it is not always possible due to physical and mental health issues. Some also noted that activities within a treatment setting can detract from therapy, support the eating disorder, or be a motivator for recovery depending on the needs and interests of the individual and how the activity is presented in therapy.

#### **4.7.6 'Communicating with others and expressing my emotions were important factors in my recovery'**

Respondents consistently agreed this was important. Respondents expressed the beliefs that communicating with others was important to help-seeking and that the eating disorder was less likely to be maintained if they communicated with others. Respondents consistently identified that the capacity to communicate with others is dependent on an individual's personality, the stigma they have experienced, and their stage of illness and recovery.

#### **4.7.7 'My treatment providers worked together with me and my family/carers to plan, implement and evaluate my treatment'**

This aspect received a mixed response. Many noted that this did not happen for them, or that they believed that it does not happen consistently in treatment.

Those respondents who saw collaboration between the therapist and the family as positive noted that this practice achieves cohesion and a consistent message enabling people to work towards the same goals.

Those who spoke positively about collaborative treatment did so with reference to treatment received as a child or young person. In the adult treatment context, many respondents described barriers to this occurring including lack of family cohesion, lack of family engagement, and the challenges of receiving treatment in a physical location far from the family home.

#### **4.7.8 'I had a realistic understanding of recovery as an ongoing process that requires sustained effort'**

Respondents had quite varied opinions on the need for a realistic understanding of recovery with some questioning whether this was actually useful in the early stages of recovery. Noting the time, effort and distress that can occur in recovery, respondents also questioned whether they would have had capacity to understand this, at all stages in their recovery.

This prompted some to discuss definitions of recovery and many to express an understanding of recovery as a fluid thing that changes over time.

Others felt that they would have liked to know what recovery really involved; *"I believed that no one recovered"*.

*“There is so much energy needed to recover and you ask ‘is it worth it?’ So yes, it is helpful to have some idea of the process of recovery”.*

Some saw the communication of realistic expectations as being part of the therapist’s role. However, many noted that unrealistic expectations, such as predictions of rapid recovery without relapse “make you feel not good enough, like you are failing at recovery”.

Focus group participants concluded that *“there can’t be any prescriptive guidelines or steps for recovery because everyone is different”.*

The idea of being ‘in recovery’ also elicited mixed responses from focus groups. The concept of recovery as an ongoing potentially life long process was positive for some participants. For example; “it reflects the ups and downs of life”. However others noted that they were motivated by the idea of full recovery and did not want to be told that they may have to live with the process of recovery for the long term.

#### **4.7.9 ‘I had flexible, multi-disciplinary treatment options available to me that were able to meet the different physical, psychological, nutritional and functional needs at each stage of my recovery’**

Responses to this were very mixed, both positive and negative, and related to the respondent’s own experience. Several noted these treatment options were not available in the area they live in. Many noted the need for treatment options to be integrated with each other, rather than having to separately source and access them. Having not experienced this for themselves, it appears participants found it difficult to consider this in the abstract.

#### **4.7.10 ‘I was able to access services as soon as I needed them, early in the development of my eating disorder and immediately during difficult times along my journey to recovery’**

Respondents indicated that this was important, but consistently said this was not happening. They noted lack of service availability and limited public health services for eating disorders. Time, finance and geographical considerations were also raised as barriers to accessing services in a timely way.

For some respondents consideration of access to treatment prompted reflection of painful experiences and stigma during their treatment.

## **5. RESULTS; THEMATIC ANALYSIS**

The following 13 themes were identified from the focus group conversation and survey results.

### **Believe in recovery...**

People’s initial concepts of recovery were strongly influenced by health professionals. If the professional didn’t believe in or understand what recovery would look like for someone with an eating disorder then this had an impact on the consumer.

### **Know eating disorders...**

The need for clinicians to have accurate, up to date knowledge of eating disorders treatment was a theme across questions. If professionals don’t know about eating disorders then they may not be able to support recovery. However, there were indications that for some consumers the most helpful professionals were those who admitted they knew nothing about eating disorders but were prepared to learn in partnership with the consumer.

### **Take eating disorders seriously...**

This theme included the need for more screening, prompting of disclosure and the need to take eating disorder symptoms seriously even if they appear mild or atypical. A core message was ‘don’t wait until we are severely unwell before you help us to recover’.

**See me as a person...**

This theme included the need for responses in treatment that focussed on the individual as a person and not simply as a diagnosis of an eating disorder.

**Focus on thoughts...**

This theme included the need for support for social goals and a shift in the focus in therapy from weight and food to eating disorder thoughts.

**Support identity...**

This theme included the need to hold onto or redefine an identity that is separate from the eating disorder.

**Language is important...**

In this theme specific examples of appropriate language were given in relation to weight, food and appearance.

**Involve family and friends...**

The vital role of family and/or friends was emphasised; as was the need of family and friends to have their own education and support opportunities.

**Enable choice...**

In this theme participants emphasised the need to learn to make their own choices and stressed that authoritarian approaches did not help them to live independently or believe in their own self efficacy.

**It's not all about food... but food is important ...**

Participants emphasised the importance of addressing the underlying issues that led to the development of the eating disorder but they also emphasised that learning practical food skills and having access to desirable food were vital.

**A service setting that is...**

Participants emphasised the need for service settings that are private, warm and physically comfortable with access to outdoor space.

**The right kind of peer support...**

Matching of people of a similar age and stage of illness and recovery emerged as an essential part of safe, effective peer support.

**Access to support 24/7...**

Participants emphasised the importance of long term access to support during and after treatment. A number of references were made about the value of telephone support.

These agreed themes formed the basis of the final review survey (see Appendix C). The survey was based on the Delphi approach, providing statements that the respondent could rate on a five point Likert Scale from Not Important to Very Important. Two questions were posed for each statement 'How important was this for your recovery' and 'How important is it that health professionals know about this'.

All participants in the focus groups agreed to take part in the review process as did some survey respondents. Only 5 of a possible group of 17 reviewers responded to the survey. Responses reflected the variations in individual experience that would be expected from people with eating disorders, however all statements were regarded as important to very important.

Of note, four themes were unanimously identified as very important:

- All of the statements about the experience of recovery:
  - recovery is freedom from the dominance of an eating disorder
  - recovery is a personal journey
  - recovery is learning alternative ways of coping
  - recovery is hard work.

- 'There's more to an eating disorder than appearance' which included a shift of focus in treatment from body image, weight and food towards eating disorder thoughts
- 'Talk to me as a person' which included allowing the person to express their views, paying attention to what they have to say and who they are
- 'Language matters' which included 'Please don't compliment my ED'.

All respondents to the review survey indicated that it is very important for health professionals to understand all these aspects of recovery. Although all aspects were noted to be important, some indicated a high to very high importance from consumers.

Based on the above and comparison with the National Framework for Recovery Oriented Mental Health Services, indications were that recovery oriented practices for people with eating disorders may differ from general recommendations for recovery oriented practice.

Based on this analysis, the priority areas for the development of the *Insights in Recovery Guide* were identified as:

- understanding recovery
- supporting disclosure
- feeling safe
- language matters
- finding identity
- integrating choice
- healthy support.

## 6. DISCUSSION

This section details interpretation of key findings and themes from the project's results. It reflects on the findings within the context of broader recovery literature. The interpretation of findings as professional practice principles can be found in the accompanying *Insights in Recovery: a consumer-informed guide for practitioners working with people with eating disorders*, and in summary in Appendix A of this report.

### 6.1 Perspectives on Recovery

Participants understood recovery to be process of regaining a satisfactory life that was no longer dominated by thoughts of food or the punitive eating disorder voice. This is consistent with the findings of other studies on recovery in eating disorders (see Malson, Bailey, Clarke, Treasure, Anderson & Kohn).

Important issues for participants included developing a sense of identity, experiencing personal agency in their recovery, supportive relationships, choice and a sense of control, confidence and hope. These themes concur with findings from earlier studies (Hay & Cho, 2013; Leung, Ma & Russell, 2012; NEDC, 2011).

These issues are also central to the model of personal recovery which encompasses a range of factors that influence quality of life, including internal personal conditions (Jacobson & Greenley, 2001). The literature on personal recovery frequently describes recovery as a process of growth towards a personally satisfying quality of life (Andresen et al., 2003; Anthony, 1993; Schrank & Slade, 2007).

A systematic review of the conceptual framework for personal recovery in mental health identified five recovery processes that are important for personal recovery in mental health in general. These are connectedness, hope and optimism about the future, identity, meaning in life and empowerment (Leamy et al., 2011).

While different terms are used for the components of personal recovery, there seems to be consensus that recovery focussed practices are those that assist people to achieve hope, identity, personal responsibility, choice, and social

inclusion (Amering & Schmolke, 2009; Andresen et al., 2003; Kogstad, Ekeland & Hummelvoll, 2011; Slade, 2009).

The belief that a satisfying life is achievable (Copic et al., 2011; Jacobson & Greenley, 2001) plays an important role in recovery as a motivator for change and a sustaining factor during the work of recovery (Andresen et al., 2003; London & Maudsley, 2010; Slade, 2009; Spandler & Stickley, 2011).

Various authors have suggested that these concepts are relevant to everyone, reflecting universal human needs rather than needs specific to mental illness (Amering, 2008; Anthony, 1993; Jacobson, 2009). The process of recovery is something experienced by all humans who are faced with difficulties. The findings of the Insights in Recovery project are consistent with this view of shared human needs to support the processes of recovery.

However, there were differences in the priority that people with eating disorders placed on aspects of healthcare and recovery support.

## 6.2 Priorities in Eating Disorders Recovery Narratives

A pervasive theme throughout all of the written and verbal narratives of recovery from eating disorders collected by this project may be summed up as 'treat me like a person'. Participants wanted to be seen as an individual person first rather than feeling categorised by their illness.

A number of principles and capabilities from the National Framework for Recovery Oriented Mental Health Services (2013) were not raised as priorities in the narratives of participants in this project including; cultural appropriateness, peer workforce and social inclusion.

No specific mention was made of culturally appropriate or gender inclusive practice. This may reflect the demographics of the project participants, however a small number of participants identified with non-binary gender and individuals participating in the focus groups were from different ethnic backgrounds.

A possible interpretation of this gap in the narratives may be found in the strong narratives around access to treatment. Several participants responding to the question on treatment (13% of 57 respondents) indicated that they had not received any form of successful treatment. Affordability of services, access to a wider range of services, access to residential models of service and access to tele-health services were all recurrent themes as barriers to treatment. For people with eating disorders, gaining access to treatment at all may be of more immediate importance than consideration of cultural appropriateness.

Formal peer support was another area in which the narratives offered limited insight. While 70% of respondents indicated that they had had contact with a person with experience of an eating disorder during their recovery, for most respondents this was not formal peer support and formal peer support was not regarded as an integral part of treatment.

When given an opportunity to specifically consider peer support, focus groups reflected both the advantages and disadvantages of engaging with peers. They concluded that peer support required careful matching of participants. They also expressed a desire to learn safe social skills so that they could make their own choices for informal peer support.

The concept of a peer workforce involved in training health professionals was strongly supported by focus group participants.

Concepts of recovery support provided after or in addition to treatment were also limited, most probably because participants had not received this support. There was clear consensus that treatment or support is required beyond the point at which weight is restored and/or eating disorder behaviours are reduced below diagnostic criteria. The narratives strongly emphasised the persistence of eating disorder thoughts after treatment and the need for access to on-going help to learn to manage these thoughts.

Support for social inclusion was not directly mentioned in participant narratives. Narratives did include reflection on the

role of stigma in inhibiting help seeking and the need to overcome stigmatising beliefs about eating disorders. Participants' concepts of quality of life included education, employment and social relationships all of which are important factors in social inclusion.

Barriers ascribed to these aspects of social inclusion related to the physical impact of an eating disorder rather than external factors. Participants described fatigue and physical illness as the reasons they did not participate in social activities. The priority practice to support social inclusion for people with eating disorders therefore could be identified as effective treatment of the eating disorder including treatment of physical health consequences.

## 6.3 Emerging Themes

### 6.3.1 Disconnected Communication

Only 1 in 10 men and women with eating disorders receive eating disorder specific treatment (Noordenbox, 2002). There are many reasons for this, one of which is an inherent characteristic of the illness itself; people with eating disorders often manifest a strong ambivalence towards treatment.

The narratives of people who have recovered or are in recovery share a slightly different perspective on their feelings towards treatment. The results clearly demonstrate the internal conflict between wanting to be well and not wanting to take the risks associated with changing their eating disorder behaviours. However, the results also describe people who are actively seeking help and often feel rejected or misunderstood by healthcare practitioners.

People described their very low self-esteem, the dominance of their eating disorder over other aspects of self, and their need to feel accepted in their relationships with healthcare professionals. Narratives defined the negative impact of feeling rejected or misunderstood on self-esteem and on future help seeking behaviour.

There was an apparent disconnect in communication between healthcare professionals and people with eating disorders. The two focal points in this disconnect were the first steps in help seeking and getting a diagnosis; and beliefs about recovery.

Narratives of help seeking, both before diagnosis and when changing health practitioners at a later stage, described a perceived lack of professional knowledge about eating disorders or knowledge limited to the physical and behavioural aspects of diagnostic criteria rather than an awareness of eating disorders as mental illnesses causing intense distress.

Communication by health professionals was frequently understood as dismissive, contributing to a delay in accessing treatment and in some instances an escalation in the symptoms and physical consequences of the eating disorder.

One of the most important consensus messages that participants wanted to communicate to health professionals was that an eating disorder cannot be identified visually and are often identified too late; *"you cannot tell if someone has an eating disorder by looking at them. Take eating disorders seriously and intervene quickly"*.

There was also an apparent disconnect between participants' understanding of recovery and their perceptions of health professionals beliefs about recovery.

For participants, recovery involved freedom from the dominance of eating disorder thoughts and achievement of a satisfying quality of life. Their experience was that this was a long process involving trial and error in which help could be required at different stages and with differing degrees of intensity.

What participants had understood from their healthcare professionals was that recovery was a relatively quick process involving changing eating disorder behaviours, and for people with anorexia nervosa, restoration of weight. This is consistent with the findings of Noordenbos and Seubring (2006), who identified that patients and clinicians can have very different opinions about what constitutes recovery.



These differences in concepts of recovery contributed to feelings of failure and worthlessness when experience did not match expectation, in some instances discouraging people from persistence in their recovery.

### 6.3.2 Feeling Safe

Participants did not directly indicate that feeling safe was a priority for recovery oriented practice. Despite this the word 'safe' emerged as a strong theme, used as a descriptor of other practices. The concept of safety was associated with relationships with health professionals and with service settings.

The prevalence of the word was noted in the translation of key themes into a practice guide and a new message was developed to try to reflect the concept of safety:

#### **Help me to feel safe**

**Help me...** the whole person in the context of my family and friends, my life and dreams

**To feel...** help me to deal with my thoughts and feelings in a positive way

**Safe...** help me to feel understood, less afraid and more hopeful in my journey through recovery

This message was reviewed by a small group of participants in the final review process. Considering the question 'how important is it for health professional to know...' they rated this message as important to very important for health professional knowledge.

## 7. LIMITATIONS

Insights in Recovery is possibly one of the largest qualitative studies of its kind in Australia, collecting a depth and diversity of eating disorder recovery narratives. Only a fraction of that data has been analysed so far, with an emphasis on the most common themes rather than on the diversity of experience.

The methodology required that participants consider themselves to be recovered or in recovery. Most of the participants had received treatment, in contrast to the expectation that only 1 in 10 people will receive treatment. These factors may make the experience of these participants different to those of people who do not receive treatment or who have a severe and chronic course of illness.

The majority of participants were female. This is consistent with diagnostic patterns; more females are diagnosed with an eating disorder than males (Hoek, 2006; Striegel-Moore & Bulik, 2007).

However, research suggests that about 25% of people with anorexia nervosa and bulimia nervosa are male, and 36% of those with binge eating disorder are male (Hudson, 2007). The sample is therefore not representative of all people with experience of an eating disorder.

Based on available demographic data (see for example, Swanson, Crow, Le Grange, Swendsen & Merikangas, 2011) there are more people in the general population with Binge Eating Disorder and Other Specified Feeding and Eating Disorders (OSFED) than there are people with Anorexia Nervosa. The prevalence of binge eating disorder in the general population is estimated to be about 4% (Grilo & Masheb, 2000).

In this study, the majority (72%) of respondents had experience of Anorexia Nervosa. In the analysis of data, no discernible difference was noted between respondents with Anorexia Nervosa and respondents with other eating disorder diagnoses; however a study with a higher rate of participation by people with diagnoses other than Anorexia Nervosa may provide different insights into the process of recovery.

A number of issues that are priorities for general recovery oriented practice in mental health, such as culturally appropriate service delivery, were not raised by participants in this study. The absence of this information should not be interpreted as evidence that people with eating disorders are not concerned about these issues.

The key themes from this study have been translated into a recovery oriented practice guide. Translation from one vocabulary to another brings its own challenges. Many participants had identified what they needed to support recovery based on negative experiences in treatment. Many of the messages in the original words of participants were avoidant messages. For example; *“Don't comment on my weight or appearance”*. Translations of these avoidant messages into more positive dialogue suggest acceptable recovery oriented practice, however; these positive practices have not been evaluated in practice.

The Insights in Recovery project methodology prioritized maintaining the integrity of the consumer narrative in the development of the *Insights in Recovery Guide* by ensuring review of key content for the Guide by consumers and by incorporating the personal voice of the consumer in the Guide. The translation process has implications for the reliability of the findings.

## 8. CONCLUSIONS

Recovery-oriented approaches in mental health treatment aim to support individuals in taking responsibility for their personal journey to recovery and offer a collaborative holistic framework to work within.

The process of recovery is something experienced by anyone faced with difficulties, and people with eating disorders identify components of recovery that are very similar to those identified by the personal recovery movement.

Overall, the data collected in the Insights in Recovery project supports the use of the personal recovery model and implementation of the National Framework for Recovery Oriented Mental Health Services (2013) as relevant to people with eating disorders.

This project has highlighted areas where recovery oriented approaches for people with eating disorders may require a different emphasis. Of particular note is the need for:

- understanding recovery; an understanding of recovery as a long term process that addresses eating disorder thoughts and quality of life issues
- supporting disclosure; positive professional responses to help seeking and self-disclosure and the prioritisation of early intervention
- feeling safe; positive professional practices that build trust and feelings of safety including a focus on the thoughts associated with eating disorders and service settings that promote feelings of safety
- language matters; the words used to communicate with a person with an eating disorder must take into consideration how language is understood through the filter of the eating disorder
- supporting identity; people with eating disorders struggle with elements of their identity. Recovery oriented practice assists people to develop their sense of identity beyond the diagnosis of an eating disorder
- integrating choice; recovery is characterised by regaining 'normal' levels of control. Recovery oriented practice helps people learn to make safe choices about their eating.
- helpful support; recovery happens in daily life more than in the clinical setting. The right type of support is important across all stages of recovery
- Informed by Lived Experience: A health workforce with knowledge of eating disorders recovery informed by the experience of people with eating disorders.

Findings from this study have informed the development of a new resource on recovery oriented practice as a companion to National Framework for Recovery Oriented Mental Health Services:

*Insights in Recovery: A consumer-informed guide for practitioners working with people with eating disorders.*

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## Appendix A. Translating Consumer Themes to Practice Guidelines

Themes from Consumer Narrative	Identified Recovery Practice Priorities	Summary of Key Professional Guidelines
<p><b>Knowledge about eating disorders</b></p> <p>Believe in recovery... People's initial concepts of recovery were strongly influenced by health professionals. If the professional didn't believe in or understand what recovery would look like for someone with an eating disorder then this had an impact on the consumer.</p> <p>Know eating disorders... Consumers said clinicians need to have accurate up to date knowledge of eating disorders treatment.</p>	<p><b>Understand Recovery</b></p> <p>An understanding of recovery as a long term process that addresses eating disorder thoughts and quality of life issues.</p> <p>A health workforce with knowledge of eating disorders recovery informed by the experience of people with eating disorders.</p>	<ul style="list-style-type: none"> <li>• Provide information on the different types of eating disorders.</li> <li>• Explain the different dimensions of recovery and why several different health professionals may be involved in their treatment.</li> <li>• Explain recovery as a non-linear process that takes time.</li> <li>• Help the person to define their own goals for recovery.</li> </ul>
<p><b>Take eating disorders seriously</b></p> <p>This theme included the need for more screening, prompting of disclosure and the need to take eating disorder symptoms seriously even if they appear mild or atypical. A core message was 'don't wait until we are severely unwell before you help us to recover'.</p>	<p><b>Supporting Disclosure</b></p> <p>Positive professional responses to help seeking and self-disclosure and the prioritisation of early intervention.</p>	<ul style="list-style-type: none"> <li>• Invite disclosure using evidence based screening tools such as SCOFF.</li> <li>• Intervene early rather than waiting for symptoms to become severe.</li> <li>• Help the person to find their own motivation for recovery. Motivational interviewing techniques are helpful.</li> </ul>

## Appendix A. Translating Consumer Themes to Practice Guidelines

Themes from Consumer Narrative	Identified Recovery Practice Priorities	Summary of Key Professional Guidelines
<p><b>Thoughts and feelings</b></p> <p><b>Feeling safe</b></p> <p>Participants emphasized the dominant role of fear, shame and guilt in their lives and the need to feel safe in order to engage in recovery.</p> <p>Focus on thoughts... This theme included the need for support for social goals and a shift in the focus in therapy from weight and food to eating disorder thoughts.</p> <p>A service setting that is... Participants emphasised the need for service settings that are private, warm and physically comfortable with access to outdoor space.</p>	<p><b>Feeling Safe</b></p> <p>People relate safety to person centred care, communication between themselves and their health professionals and to the service setting</p>	<ul style="list-style-type: none"> <li>• Good general professional practice including compassion, calmness, honesty and caring.</li> <li>• Listen without judgement allowing people to voice their concerns.</li> <li>• Listen to the distress that people experience without negotiating with the eating disorder.</li> <li>• A sense of humour can help to alleviate tension.</li> <li>• Be firm and empathetic on what constitutes appropriate behaviour in the treatment setting.</li> <li>• Focus on the thoughts associated with eating disorders more than weight and appearance.</li> <li>• Increase opportunities for positive behaviours that are unrelated to food.</li> <li>• Provide a physically warm, comfortable and relaxing environment.</li> <li>• Offer maximum privacy.</li> <li>• Foster a community atmosphere</li> </ul>



## Appendix A. Translating Consumer Themes to Practice Guidelines

Themes from Consumer Narrative	Identified Recovery Practice Priorities	Summary of Key Professional Guidelines
<p><b>Communication</b></p> <p>Language is important... In this theme specific examples of appropriate language were given in relation to weight, food and appearance.</p>	<p><b>Language Matters</b></p> <p>Words and language used can affect recovery efforts by focussing attention on hope, growth, empowerment, and building self-identity.</p> <p>Language that focuses on food, weight and appearance may be interpreted as complimenting the eating disorder</p>	<ul style="list-style-type: none"> <li>• Use person-first language that acknowledges the person as more important than the eating disorder.</li> <li>• Use accurate descriptive language rather than labels.</li> <li>• Notice and comment on achievement in all elements of recovery not just on weight and eating.</li> <li>• Use positive and motivating language that builds hope.</li> <li>• Ask open questions and allow for choice wherever possible.</li> <li>• Try to avoid making comments about weight or appearance.</li> <li>• Shift the focus of discussion from food and exercise onto a wider view of all facets of recovery.</li> <li>• Substitute words like 'try' and 'could' for words like 'should' and 'must'.</li> <li>• Try to ask a question rather than making direct comments</li> </ul>

**Appendix A. Translating Consumer Themes to Practice Guidelines**

<p><b>Themes from Consumer Narrative</b></p>	<p><b>Identified Recovery Practice Priorities</b></p>	<p><b>Summary of Key Professional Guidelines</b></p>
<p><b>The person behind the eating disorder</b></p> <p>See me as a person... This theme included the need for responses in treatment that focussed on the individual as a person and not simply as diagnosis of an eating disorder.</p> <p>Support identity... This theme included the need to hold onto or redefine an identity that is separate from the eating disorder.</p>	<p><b>Finding Identity</b></p> <p>‘Talk to me as a person’ allowing the person to express their views, paying attention to what they have to say and who they are.</p>	<ul style="list-style-type: none"> <li>• Learn about your patient as a person - their interests, hobbies, likes and talents.</li> <li>• Talk to their family to learn more about them.</li> <li>• Provide opportunities to help reconnect the person to their interests.</li> <li>• Build a strong therapeutic alliance through genuine connections and by letting your patients see you as a whole person</li> </ul>

## Appendix A. Translating Consumer Themes to Practice Guidelines

Themes from Consumer Narrative	Identified Recovery Practice Priorities	Summary of Key Professional Guidelines
<p><b>Enable choice</b></p> <p>In this theme participants emphasised the need to learn to make their own choices and stressed that authoritarian approaches did not help them to live independently or believe in their own self efficacy.</p> <p>It's not all about food... but food is important ...</p> <p>Participants emphasised the importance of addressing the underlying issues that led to the development of the eating disorder but they also emphasised that learning practical food skills and having access to desirable food were vital.</p>	<p><b>Integrate choice</b></p> <p>Recovery is characterised by regaining 'normal' levels of control (or exercising choice). Helping people learn to make safe choices promotes recovery.</p>	<ul style="list-style-type: none"> <li>• Empathise with each person in their unique situation.</li> <li>• Provide clear meaningful reasons for treatment (and other) decisions.</li> <li>• Actively include people in the development of their treatment plan and match the types of choices relating to eating behaviours to the stage in the treatment process.</li> <li>• Build in choices in areas of life unrelated to eating behaviour.</li> <li>• Encourage autonomy building behaviour and communication from parents and peers</li> <li>• Avoid coercive language, controlling rewards, inducing guilt or shame.</li> <li>• Provide access to palatable food. When eating is a goal of treatment food needs to be desirable.</li> <li>• Provide healthy food choices wherever possible.</li> <li>• Provide skills based learning on the preparation of food and on social eating</li> </ul>

## Appendix A. Translating Consumer Themes to Practice Guidelines

Themes from Consumer Narrative	Identified Recovery Practice Priorities	Summary of Key Professional Guidelines
<p><b>A holistic approach</b></p> <p>Involve family and friends... The crucial role of family and/or friends was emphasised; as was the need of family and friends to have their own education and support opportunities.</p> <p>The right kind of peer support... Matching of people of a similar age and appropriate stage of illness and recovery emerged as an essential part of safe, effective peer support.</p> <p>Access to support 24/7... Participants emphasised the importance of long term access to support during and after treatment. A number of references were made about the value of telephone support.</p>	<p><b>Healthy support</b></p> <p>Recovery happens in daily life more than in the clinical setting. The right type of support is important across all stages of recovery. Sources of support include professional support services, health professionals, peers, family and friends.</p>	<ul style="list-style-type: none"> <li>• Work to establish trust through use of empathy and encourage help-seeking.</li> <li>• Create opportunities for well-matched (and safe) peer support.</li> <li>• Consider providing training for peer-support workers to provide safe peer support.</li> <li>• Help people with eating disorders learn how to develop safe relationships with appropriate boundaries.</li> <li>• Encourage people to build (or rebuild) relationships with family and friends.</li> <li>• Provide information on safe online communities</li> </ul>

## Appendix B: Survey – Narrative Questions

Q1 For our information: Have you previously submitted a response to this survey?

Q2 What is your age?

Q3 What is your gender?

Q4 List your city, state or territory, and country of residence.

Q6 Over what time period did/has your experience of an eating disorder span/spanned?

Q7 In your own words describe where you are in your journey of recovery.

Q8 List all the different treatments you have accessed throughout your journey of recovery.

Q9 Describe the most important details of your experience, including events, conversations, treatment settings and timelines.

Q10 Describe what you would consider the most relevant or important thoughts and feelings that accompanied these experiences.

Q11 Has your interpretation of any of these details changed over time?

Q12 Take a moment to reflect back on the most and least helpful aspects of your recovery journey. How did you recognise helpful people along your recovery journey and what actions or words made these people most helpful?

Q13 What contributed to helpful treatment settings?

Q14 What were the most helpful things that you did for yourself along your recovery journey?

Q15 In what ways did professionals and/or organisations assist your recovery the most throughout your treatment?

Q16 In what ways did non-professionals assist in your recovery journey?

Q17 What aspects of your life other than treatment contributed positively to your recovery?

Q18 What role have family and friends played in your recovery?

Q19 What were the least helpful aspects of your recovery journey?

Q20 Which of the following ten aspects of recovery-oriented treatment would you say would help a person recover from an eating disorder regardless of their treatment pathway; and in what ways do the following statements relate to your personal recovery experience? Professionals communicated positive expectations, hope and optimism.

Q21 Professionals made me feel valued, important, safe and welcome.

Q22 The treatment I received was holistic and person-centered, meaning that I was put first and was at the centre of the care I received.

## Appendix B: Survey – Narrative Questions

Q23 I felt motivated by a personal desire to recover and a belief that this was achievable. I took personal responsibility for my recovery.

Q24 Focusing on my strengths and working on developing activities, hobbies, interests and social relationships outside of my eating disorder were important factors in my recovery.

Q25 Communicating with others and expressing my emotions were important factors in my recovery.

Q26 My treatment providers worked together with me and my family/carers to plan, implement and evaluate my treatment.

Q27 I had a realistic understanding of recovery as an ongoing process that requires sustained effort.

Q28 I had flexible, multi-disciplinary treatment options available to me that were able to meet the different physical, psychological, nutritional and functional needs at each stage of my recovery.

Q29 I was able to access services as soon as I needed them, early in the development of my eating disorder and immediately during difficult times along my journey to recovery.

Q30 Did you at any stage have contact with someone who had recovered from an eating disorder?

Q31 If yes, did this contact help you and in what way?

Q32 If no, would you have liked to and in what way do you think this contact might have been helpful?

Q33 In what ways could professionals and/or organisations have assisted your recovery more effectively throughout your treatment?

Q34 In what ways could non-professionals have been of greater assistance throughout your journey of recovery?

Q35 In what ways could other aspects of your life have contributed more effectively to your recovery?

## Appendix C: Survey - Review of key themes

### Draft Statements for a Consumer Delphi Process

#### Group 1: Statements about recovery from eating disorders

"I wish that health professionals knew that..."

##### Recovery is freedom from the dominance of ED

- Recovery is when ED thoughts are not at the forefront of your mind
- Recovery is freedom – breaking free of illness to be yourself
- Recovery is finding who you are. Not just your body but who you really are as a person
- The thoughts get worse as eating gets better. People need support during the stages of recovery.

##### Recovery is a personal journey

- Recovery is not a goal post to be passed or a rigid plan to be achieved
- Recovery is a process and a journey that will be different for each person
- Recovery is working towards your own life goals and gaining a fulfilling life
- Recovery is a process of experimentation – of trial and error – and there needs to be room to try different approaches

##### Recovery is learning alternative ways of coping

- Recovery is learning strategies to control your thoughts and sources of stress
- Recovery is resolving the underlying issues that started the ED

##### Recovery is hard work

- Recovery is hard work and sometimes you question if it is all worthwhile
- The idea of being in recovery is useful. It reflects the ups and downs of life.
- It is helpful to have some idea of the process of recovery.
- Having small practical steps and milestones to achieve is a good approach to recovery
- Part of recovery is learning that if I go backwards I can still move forwards again towards my goals

#### Group 2: Statements about seeking help for an eating disorder

"I wish that health professionals knew that..."

##### My life was dominated by fear

- I felt intimidated and scared of what would happen in treatment
- I was afraid that I would do something wrong or not be good enough
- I felt I had to be perfect to be accepted
- I felt deeply ashamed and this made it difficult to talk about my ED

##### It is very difficult to ask for help

- I felt I couldn't seek help because I didn't deserve it
- Every time I tried to get treatment and failed I felt a sense of failure and hopelessness
- I want to be well but I also don't want to deal with change

##### There's more to an ED than appearance

- Body image and social pressure isn't an issue for everyone. There are other reasons for developing an ED.
- Appearance isn't a good indication of the severity of illness. You cannot tell whether someone has an eating disorder just by looking at them.

- Being in treatment can make you feel like a failure
- It can feel in therapy like the pressure is really on you to perform and therefore you can also feel like a failure.
- Losing control can feel like a nightmare and make feelings of fear, shame, worthlessness and ambivalence about recovery stronger

### Group 3: Statements about professional knowledge and behaviours

#### Engage with the whole person

*"It helps me to recover when health professionals do this..."*

#### Get to know who I am and who I want to be in the future

- Get to know about me as a whole person and not just as a stereotype of an ED
- Learn about who I was before the ED
- Help me to regain a sense of self that is distinct from my ED
- It's easy to forget who you are in treatment.

#### Work in partnership with me

- Be open to learning about eating disorders in partnership with me
- Negotiate goals and milestones that have meaning for me
- Identify social goals that help me to get back into regular life
- Work at my pace rather than setting a fixed pace of recovery for everyone

#### Talk to me as a person

- Allow me to talk without expressing judgement
- Listen to me and value what I have to say - If people didn't pay attention to what I had to say and who I am then I would take it on board that I wasn't interesting enough.
- Ask me about my thoughts
- Engage in some ordinary everyday conversation rather than just talking about my ED

#### Language matters

*"It helps me to recover when health professionals avoid..."*

#### Please don't compliment my ED

- Making remarks about weight or appearance, even saying 'you look good today', may sound like a comment about weight.
- Complimenting my willpower is complimenting my ED
- Shift the focus of discussion away from food. Focus on the other things that are motivating to build a new life
- Comparisons with other people, for example; 'you are fatter/thinner than the other person' or 'you don't look anorexic' make me feel like a failure

#### Provide opportunities for people to make safe healthy choices

*"It helps me to recover when health professionals..."*

#### Integrate choice wherever possible

- With an ED people feel they have to live by rules. Avoid substituting rigid treatment rules or recovery goals for the ED rules.
- Make positive suggestions such as 'you could' or 'try this' rather than using 'should' and 'must' especially in relation to food and exercise.
- Ask open questions to help me recognise the issues for myself.
- Increase opportunities for positive behaviours that are unrelated to food



### **Help me to learn how to make choices**

- Value a broad range of achievements as evidence of my progress in recovery, not just ED behavioural or physical changes
- Ask what I am comfortable with as my next step in recovery
- Allow me to share my views and to disagree with you
- Help me to take ownership of my recovery

### **Establish clear boundaries**

- Listen to the distress that I am experiencing during treatment but don't negotiate with the eating disorder
- Establish clear boundaries on what constitutes 'recovery and appropriate behaviour
- Be firm and empathetic about the things I need to do to get well

## **Group 4: Statements about service settings and service systems**

### **Workforce development**

*"It is helpful when service providers..."*

- Provide professional development in eating disorders for all their staff
- Involve people who have recovered from different eating disorders in the provision of training and mentoring for professionals
- Enable collaborative treatment involving different professionals and family members
- Food Practices
- Provide access to palatable food. When eating is a goal of treatment food has to be desirable.
- Provide meal support including support for people who are living in the community (For example; for students returning to school)
- Provide skills based learning on the preparation of food and on social eating

### **Service settings**

*"It is helpful when the service setting is..."*

- Physically warm, comfortable and relaxing
- Has access to the natural environment, sunlight and fresh air
- Offers maximum privacy
- Has a community atmosphere

### **Peer Support**

*"It is helpful when services provide..."*

#### **The right kind of peer support as an integral part of treatment**

- Match peer group members for similar stages of recovery
- Train peer leaders who have a variety of different experiences of illness
- Provide online access to peer support where face to face support is not practical

#### **Help me to make healthy peer friendships**

- Support healthy peer friendships within group treatment settings
- Educate people in how to maintain safe boundaries when forming relationships

#### **Access to support**

*"It is helpful when services provide or help us to access..."*

- Long term support during recovery

- Out of hours support (For example; telephone support)
- Education and support for family and friends whether they are involved in supporting recovery or not

**Help me to feel safe**

**Help me...** the whole person in the context of my family and friends, my life and dreams

**To feel...** help me to deal with my thoughts and feelings in a positive way

**Safe...** help me to feel understood, less afraid and more hopeful in my journey through recovery





## Butterfly

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