2021

Real World Solutions for Eating Disorders Early Intervention

Sunshine Coast Eating Disorders Access Trial

REPORT TO THE COMMONWEALTH DEPARTMENT OF HEALTH AND THE BUTTERFLY FOUNDATION

Final Report
30 September 2021

Purpose and Scope of this Report

The Sunshine Coast Eating Disorders Access Trial (the Trial) was funded by the Australian Department of Health to improve access to evidence-based multidisciplinary treatment for people with eating disorders. This real-world opportunity was used to investigate the practical barriers and facilitators to accessing effective treatment through primary and allied health care service providers.

A consortium of evaluation, research and eating disorder experts, including Flinders University of South Australia and the University of Sunshine Coast, has evaluated the outcomes of the Trial. Evaluation objectives have included investigation of:

1. The safety and effectiveness of Trial strategies and their impact on individuals with eating disorders and their families, service providers and health systems.
2. The role of affordability and professional development in accessing treatment for eating disorders.
3. Other factors that influence access to treatment for eating disorders.

This report discusses the results of the Trial and outlines options for sustained implementation of the Trial's achievements in the region and nationally, including areas where further research is required.

The report is based on data to 18 August 2021. The Trial will continue to 30 September 2021.

Lesley Cook
Partners in Practice Blackboro Associates Pty Ltd
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Authors:

Lesley Cook, Partners in Practice
Catherine Johnson, Flinders University
Tracey Wade, Flinders University
Kath Cadman, Butterfly Foundation
Thu Andersen, Butterfly Foundation
Ben Lane, University of Sunshine Coast

Terminology

In this report the term 'client' is used to refer to someone receiving treatment for an eating disorder. The term 'service provider' is used collectively to refer to all the health professions who registered with the Trial to deliver eating disorders treatment.

Executive Summary

Eating disorders are serious illnesses that often start in adolescence or early adult years and persist for many years. Having an eating disorder can affect every area of physical and mental health. Interrupting the cycle of illness early is important. This is the best evidence-based approach to reducing the impact of illness in individual lives and reducing the high costs of healthcare associated with eating disorders.

Most people with eating disorders (90%) do not receive treatment for their illness although they do use health services more frequently than the general population. The small percentage accessing treatment are often severely unwell or people who have had the illness for several years. It is vital that we develop our understanding of how to get treatment to people with or at risk of eating disorders as early as possible.

The Trial has taken a practical look at enabling primary and allied health providers to improve rates of early identification and access to evidence-based treatment. It was designed to address the priority barriers of finding a clinician, cost of treatment and navigation of the health system. Over a period of 28 months, 303 referrals were received, with 215 people starting treatment through the Trial and a further 78 people receiving support to find alternative treatment options.

The positive treatment outcomes for clients in the Trial compare favourably with those of clinical research trials, demonstrating that treatment can be delivered safely and effectively in non-specialist community settings. These outcomes were achieved with some specific support strategies. Evaluation of the Trial highlights the following practices as important contributors to the safety and effectiveness of eating disorders treatment:

1. Training
The client outcomes of the Trial were achieved through a cohort of trained and registered service providers. This was essential to meet national competency standards and match the requirements for MBS eating disorder item numbers. A minimum of 13 hours of training was required. The format of locally delivered and online training attracted high rates of participation and was successful in developing a pool of skilled service providers for the region. Credentialing is a vital first step to improve access to evidence-based treatment.

2. Reduced Treatment Costs
Eating disorder treatment is intense, multi-disciplinary and often of long-duration and this is reflected in the costs of treatment. More than half (63.9%) of Trial clients were on low incomes. The Trial provided MBS equivalent rebates for treatment for clients who were otherwise not eligible for MBS rebates. Additional help was provided to locate bulk billed or low-gap payment services. It is estimated that as many as 90% of Trial clients would not have been able to complete a full course of treatment without access to rebates. Access to low-cost treatment is essential at every stage of illness including early intervention to reduce the risk of chronicity.

3. Core treatment practices

All evidence-based therapies work towards eating and weight normalisation early in treatment using some consistent practices such as measuring client progress in these domains. The Trial found that focusing on key practices provided a practical approach to reviewing the integrity of treatment. The Trial has demonstrated that regular weighing (at 50% or more of sessions) influences treatment outcomes favourably, particularly in relation to reducing weight concerns.

4. Integrated team care

The national standards for eating disorders care include a multi-disciplinary approach to treatment and this requires frequent communication between service providers. The Trial recommended regular case conferencing to support communication, paying rebates to all treatment team members who participated. This has emerged as a significant moderator of treatment outcomes, with clients whose service providers met two or more times over a course of treatment demonstrating better treatment outcomes. Dietetic care also emerged as a moderator of treatment retention. Clients who received three or more sessions with a dietician were less likely to drop out of treatment prematurely.

5. Screening and assessment pathways

The Trial promoted screening for early identification and supported GPs to identify and refer for assessment. Overall, 70% of Trial clients had not previously received treatment. In a sample of referrals from GPs participating in the screening initiative, this increased to 83% who had not previously been diagnosed or received treatment. The Trial's provision of pathways to assessment and treatment played a critical role in engaging GPs and other referrers.

6. Care navigation

The barriers to accessing treatment for eating disorders include finding a clinician who treats eating disorders, the cost of treatment, waiting lists, location of services and eligibility criteria that restrict access to the most severely unwell. An additional systems level barrier to treatment access has emerged during the Trial and that is the need for connecting mechanisms, linking service providers together. The Trial engaged a Care Navigator/Coordinator to act as a central point of contact for service providers and clients, negotiating treatment pathways for each client. Local knowledge has been essential to build relationships with service providers, and rapidly negotiate viable treatment teams and affordable care. Service providers identified the Care Navigation as the single most important single component of Trial activity after the provision of rebates.

Meeting the Needs of Clients with Complex Needs

The clients who accessed treatment through the Trial had a high rate of comorbid mental health conditions (90.5%) and a variety of other life complexities including physical illness, trauma, lack of family support and financial difficulties.

This complexity made a difference to how they engaged with treatment and is an important theme throughout this report. Eating disorders do not occur in isolation and access to treatment must consider the whole picture of the complexity of each person's life. Definitions of complex cases of

eating disorders need to reflect the impact of other issues on help-seeking and ability to complete treatment.
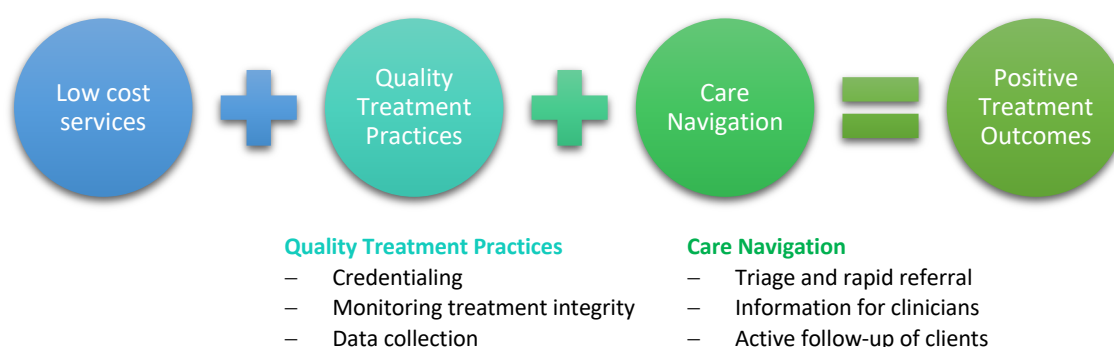
Removing Barriers to Treatment Access

The Trial has demonstrated that in a real-world context, supporting implementation of good practice principles as defined by the Australia and New Zealand Academy for Eating Disorders (ANZAED) and the National Eating Disorders Collaboration (NEDC), can address three important issues in improving access to treatment and treatment outcomes:

1. Recruiting a sufficient number of clinicians with the knowledge and skill to treat eating disorders.
2. Engaging and retaining clients in treatment, reducing premature withdrawal.
3. Achieving rates of symptom remission that compare favourably with research trials.

The Trial also demonstrates the need for and viability of service models that support rather than restrict early help-seeking. Models of early intervention are needed that reflect the complexity of presentation and the diversity of clinical significance in the early stages of developing an eating disorder. Screening and two assessment sessions provided by the Trial have both effectively increased rates of early intervention. Integrated treatment pathways are essential for people with complex presentations, even at the early intervention stage, offering a full course of treatment (20-40 sessions psychotherapy). Further initiatives are required to ensure that people on lower-than-average incomes and with complex needs have access to affordable care.

The Trial outcomes confirm that the cost of treatment and finding a trained and credentialled treatment provider are priority issues in determining access to evidence-based treatment for an eating disorder. Strategies such as the introduction of MBS rebates and the proposed national credentialing program are targeting important barriers to treatment access. The third factor that has emerged through the Trial is the need for connection. Local care navigation enabled people to access the right treatment and supported service providers to deliver that treatment within the existing health care system. Given the complexity of presentations for people seeking help for an eating disorder, the prevalence of lower-than-average income, and the importance of early intervention to reduce the impact of the illness on health and social development, continuing to find ways to offer affordable early intervention is important.

Figure 1: Essential Factors in Improving Access to Eating Disorder Treatment

Quality Treatment Practices
- Credentialing
- Monitoring treatment integrity
- Data collection

Care Navigation
- Triage and rapid referral
- Information for clinicians
- Active follow-up of clients

Contents	Page

Improving Access to Treatment

Eating disorders will affect about 10% of Australians at some point in their lives (Fairweather-Schmidt and Wade, 2014). When people cannot access the right type of treatment early in illness they have poorer health (Byrne, Fursland, Allen, and Watson, 2011) and social development outcomes (Wade, Calvert, Wild et al., 2021) with long term implications for the individual's quality of life and for health care costs. All eating disorders are likely to be chronic conditions lasting for five or more years (Zweig and Leahy, 2012). Around 20% of people will experience a persistent illness beyond 10 years (Eddy, Tabri, Thomas et al., 2017). While eating disorders do improve over time for many sufferers, very few people achieve full remission of symptoms without intervention (Wade, Bergin, Tiggemann, et al., 2006).

Background

Eating Disorders are a group of disorders that share a common core psychopathology centred on food, eating and body image concerns and disturbed food related behaviours. These are complex and dynamic disorders, in which medical, nutritional, mental health and social influences interact to sustain the illness. All diagnoses are associated with significant physical health complications and nutritional health issues (Hay, Chin et al., 2014).

Most people with eating disorders will not receive appropriate treatment. Studies suggest that less than a quarter (23%) of people with eating disorders will seek treatment (Hart, Granillo, Jorm, & Paxton, 2011), although they will use health services more frequently than the general population (Striegel-Moore, DeBar, Wilson et al., 2008). The minority of people who do seek help for an eating disorder wait for an average of 2.5–6 years before accessing treatment (Flynn, Austin, Lang et al., 2020). Around 10% will receive an evidence-based treatment specific to eating disorders (Cooper and Bailey-Straebler, 2015; Weissman and Rosselli, 2017).

> "*People with eating disorders and their families do not have reliable access to safe evidence-based treatment and support when they need it, early in illness and early in subsequent episodes of illness.*" (National Eating Disorders Agenda, Butterfly, 2017)

Improving the rate of access to treatment is expected to reduce the burden of disease for the individual, the health care system, and the community (Moessner and Bauer, 2017). The Trial has focused on barriers and facilitators of access within the health system.

The Trial aimed to find practical solutions to the immediate problem of improving access to treatment for people with eating disorders in the context of regional primary and allied health care services. This report presents the outcomes of Trial activities to reduce barriers, makes recommendations on the type of practices needed to facilitate access, and explores other factors which may limit access to treatment.

Data Collection Methods

Primary data collection methods for this report have included online and telephone surveys. Service providers participated through online surveys, interviews and focus groups.

Secondary data used in this report was provided by the Butterfly Foundation based on deidentified records maintained by the Trial. The Trial collected both qualitative and quantitative data from multiple sources.

Health information collected includes the results of psychological assessment tools administered by the treating service provider before treatment and during treatment. The Trial requested that service providers use the following assessment tools:

- *Eating Disorders Examination (EDE-Q):* a self-assessment questionnaire identified as a valid instrument to assess levels of eating disorder psychopathology (Aardoom, Dingemans et al., 2012)
- *The Depression, Anxiety and Stress Scale (DASS 21):* a self-report questionnaire providing a measure of severity of a range of symptoms common to depression, anxiety, and stress.
- *ED15 Questionnaire:* a measure of eating disorder behaviours and cognition for use during every therapeutic session (Tatham, Turner, Mountford et al, 2015).

Other sources of deidentified client data included:
- Case conference reports
- Care navigation case files
- Evaluation feedback from training activities
- Steering Committee minutes of meetings

A Delphi study commenced in 2019 to provide a systems context for the data collected by the Trial. AcciMap methodology, which draws on systems thinking as its theoretical basis, was used to provide a framework to understand the complexity of systems barriers and facilitators to treatment access. It involves identifying influencing barriers and facilitators from decisions and action made by governments, regulatory bodies, organisations, service teams, peers, family, and individuals, as well as factors associated with the technical components of the system, such as infrastructure (Lane, Read, Cook and Salmon, 2020; Svedung and Rasmussen, 2002).

Ethics approval was granted by the Bellberry Human Research Ethics Committee on 7th January 2019. All service providers and clients provided informed consent for their deidentified data to be used and consent to be contacted by the external investigative team for participation in surveys, interviews, or group discussions.

The Challenges of a Real-World Approach

The Trial is a 'real world' investigation, with activities based as far as possible on existing resources within the Sunshine Coast region, monitored and responded to in 'real-time'. This approach enables comparison between research findings and the everyday realities of service delivery in a specific context as has been successfully showcased in the Improving Access to Psychological Therapies (IAPT) scheme in the United Kingdom (Clark et al, 2017). Real world data helps to bridge the translational gap between research and practice and is an increasingly important component of health research, where there is a need for information on how treatments are used and what works safely and effectively in different contexts.

The real-world approach lacks the linear structure of a pilot project or clinical trial as there are many variables beyond the control of the project. The Trial experienced difficulties in collecting consistent data across different private practices. The data available is therefore 'messy' having missing entries, different interpretations of values and a large volume of qualitative content. Sample sizes referred to in this report therefore vary depending on the availability of data for each measurement discussed. In the absence of consistent post-treatment data, Last Observation Carried Forward was used to make pre-post comparisons for everyone who started receiving a service.

Analysis of available client data was completed for two groups: (1) an Intent to treat (ITT) group was used in which all clients who entered treatment were analysed regardless of any subsequent deviations from planned treatment; (2) a completer group where completion was defined as either the client and service provider(s) agreement that client was ready for discharge or the client discontinued treatment after ten or more sessions with a decrease in eating disorder symptoms reported in case notes; a combination that represents those considered to have received a sufficient dose of treatment.

Growth modelling for sessional Eating Disorder Cognitions (ED15; a measure of body dissatisfaction, weight preoccupation and importance of weight and shape) was undertaken in R statistical package (version 4.0.3) for both the Intent-to-treat sample (N = 157 closed cases) and for Completers (N = 106). Use of autoregressive correlation and use of both linear and quadratic models improved model fit and was applied to all models.

In the absence of adequate baseline data, a literature scan was used to establish a probable baseline.

The Sunshine Coast Region

The Sunshine Coast region is in Queensland approximately 100km north of Brisbane. The developed coastal city of Sunshine Coast has a population of 351,424 in 2021 (Sunshine Coast Council). The Relative Socio-Economic Advantage and Disadvantage index (IRSAD) for Sunshine Coast local government region is close to average at 999, compared to the capital city Brisbane at 1060. Inland areas of the region typically have a lower index between 637 and 715. Postcodes in the area serviced by the Trial had Socio-Economic Indexes for Areas (SEIFA) scores between 2 and 8. Postcode information was available for 216 clients in the Trial. Of this number, 29.8% came from areas with a SEIFA score of 5 or lower (the lowest possible score being 1 and the highest possible score being 10).

The highly developed and growing coastal area stretches 55km from Caloundra to Noosa. Hinterland towns include Beerwah, Landsborough, and Maleny. The region also includes more remote inland communities, notably the regional town and surrounding region of Gympie with a population of approximately 51,578 in 2018 (ABS, 2019). Approximately 3.9% of the population identify as Aboriginal or Torres Strait Islander which is consistent with the average in Queensland. The town of Gympie is located 93 km from the Sunshine Coast University Hospital. Gympie has a SEIFA score of 2, placing the area at the lowest end of the range.

The Sunshine Coast region has five public hospitals, including the Sunshine Coast University Hospital, a tertiary training hospital. The region's proximity to Brisbane increases access to services in the metropolitan area.

An adult eating disorder outpatient service commenced in late 2018, delivered by the Sunshine Coast Hospital and Health Service. The area is also served by tertiary support from the Queensland Health Eating Disorder Service (QuEDS) and by the Eating Disorders Queensland (EDQ) telehealth service.

At the start of the Trial, no data was available on the number of people receiving eating disorders treatment through primary and allied health care. Preliminary data from Queensland Hospital Admitted Patient Data Collection (QHAPDS) show that rates of admission for eating disorders had more than doubled in the region between 2015 and 2017 (71 admissions in 2015 and 165 in 2017).

The Sunshine Coast area is representative of developed regional communities in Australia, with well-resourced centrally located health services and areas of disadvantage further away from the highly populated coastal areas. Eating disorders had been identified as a local health issue of concern and the Trial commenced at the same time as Queensland Health services for eating disorders.

Chapter 1: Removing Barriers to Treatment Access

Some aspects of the health care system can act as barriers to treatment access. For people with eating disorders the challenges start with securing an accurate diagnosis and finding a clinician who treats eating disorders. These barriers are compounded by the cost of treatment, waiting lists, location of services and eligibility criteria that restrict access to the most severely unwell. People with eating disorders feel intense shame and a reduced ability to negotiate their way around these barriers.

The Trial was designed to address the priority barriers of finding a clinician, cost of treatment and navigation of the health system. Chapter 1 looks at the known barriers and facilitators of treatment access and describes the model used by the Trial to address these barriers.

Many factors have been identified that restrict access to eating disorders treatment. Some are found in the characteristics of eating disorders, while others are found in the structure of the health care system and broad social influences (Kastner, Weigel, Buchholz et al., 2021). System barriers that are known to reduce access to treatment include the cost of treatment, waiting lists, location of services and eligibility criteria (Akey, Rintamaki and Kane, 2013).

1.1 Identifying Barriers in the Sunshine Coast Region

The Sunshine Coast Eating Disorders Mental Health Professional Network contributed perspectives on barriers and facilitators to treatment access before the Trial commenced, to provide a benchmark for the Trial. The barriers identified cover the same issues as those in the research literature, focusing on cost of treatment, the benefits and challenges of multi-disciplinary team treatment, and the risk of burnout and isolation for service providers. Feedback emphasised the interconnectedness of barriers; the sum of challenges faced by both clients and service providers represents a more formidable barrier than any individual issue. The groups collective feedback appears

These barriers were confirmed by two investigations within the Trial: a small Delphi study involving local and national stakeholders and an exit survey of clients who had participated in the Trial.

The Delphi study was initiated to provide a systems context for the data collected by the Trial. Participation was invited from individuals representing nine different perspectives on eating disorders: general medical practice, psychiatry, psychology, dietetics, carer and lived experience, state-based public health, the local primary health network, and national and state-based leadership and non-government organisations.

Participants in the Delphi study identified a total of 81 barrier and 82 facilitator themes, with most concentrated at the Local Region Organisations, Government, and Management and Service Delivery levels. Of these themes, 15% of barriers and 6% of facilitators related to individuals. These findings shift the focus from characteristics of individuals to systemic barriers to service access (Lane et al., 2020; Regan, Cachelin and Minnick, 2017).

The summary of barriers and facilitators in Table 1 is grouped by service availability which has an impact on all stakeholders, challenges faced by service providers and challenges faced by people with eating disorders. Key themes include a lack of service availability and the lack of training and networking to support service providers. Personal experiences include the cost of treatment and the inhibiting sense of shame experienced by people with eating disorders.

Table 1: A Summary of Systems Barriers and Facilitators

Systems Barriers to Access	Systems Facilitators of Access
Service Availability - Inadequate levels of service to meet demand - Eligibility criteria requiring severe illness - Lack of inclusion of lived experience, including lack of access to peer work and family support - Medical and generalist models of care - Over-reliance on private practice	- ED identified as core business - Service hubs - Butterfly helpline - Eligibility criteria that support early intervention - Peer consultation; lived experience and service professional collaboration - Patient advocacy
Service Providers - Limited access to training for service providers - Financial disincentives to specialise in eating disorders - Lack of networks and collaboration between service providers - Out-of-session requirements; challenges in providing intensive, time consuming eating disorders treatment - Overvaluation of weight - Refusal to treat eating disorders - Fragmentation within treatment teams	- Increasing awareness of eating disorders and recognition of urgency of treatment - Credentialing project - Practice guidelines - Integrated teamwork and coordinated care; - Choice of evidence-based model; Flexible approaches in treatment - Confident service providers
Personal Barriers - Lack of inclusion of families - Cost of treatment - Location of treatment and limited ability to travel - Shame and fear of disclosing eating disorder	- Financial means - Capacity to have time off school or work - Telehealth - Support from family, peer worker or support service - Severe illness necessitating treatment

Exit interviews post treatment provided insight into their perception of barriers and facilitators of access. Table 2 summarises the key themes from a sample of 59 responses.

Table 2: Client perspectives of barriers and facilitators

Barriers Perceived by Clients	Responses	%
Cost – out of pocket expenses for treatment	50	87.75%
Lack of access e.g. transport, hours of service	20	33.90%
Comorbid conditions	17	28.81%
Fear and shame e.g. fear of judgement; of being weighed	15	25.42%
Resistance to treatment/difficulty being honest	8	13.56%
Facilitators Perceived by Clients		
Care navigation support	31	52.54%
Integrated team care	23	38.98%
Telehealth access	14	23.73%
Dietitian	12	20.34%
Finding the right clinician	10	16.95%
Motivation and timely access to treatment	10	16.95%

"I've never gone long without therapy. The biggest challenges were the cost and finding someone with the right knowledge to provide treatment"
(Client with a 32-year history of eating disorder)

The two dominant themes in both barriers and facilitators are the affordability of treatment and support to navigate the system and find a knowledgeable service provider.

The review of barriers both before and during the Trial confirms the basis on which the Trial was designed. The Trial started from the hypothesis that cost of treatment combined with the challenges of finding a service provider who is skilled to diagnose an eating disorder and deliver evidence-based treatment, intersect to restrict treatment access. The aim was to improve access to treatment by removing four systemic barriers: securing an accurate diagnosis, availability of multi-disciplinary treatment, cost of treatment, and intensity of treatment (number of treatment sessions).

Mental Health Professional Network: Perspectives on Treating Eating Disorders in Sunshine Coast Prior to 2019
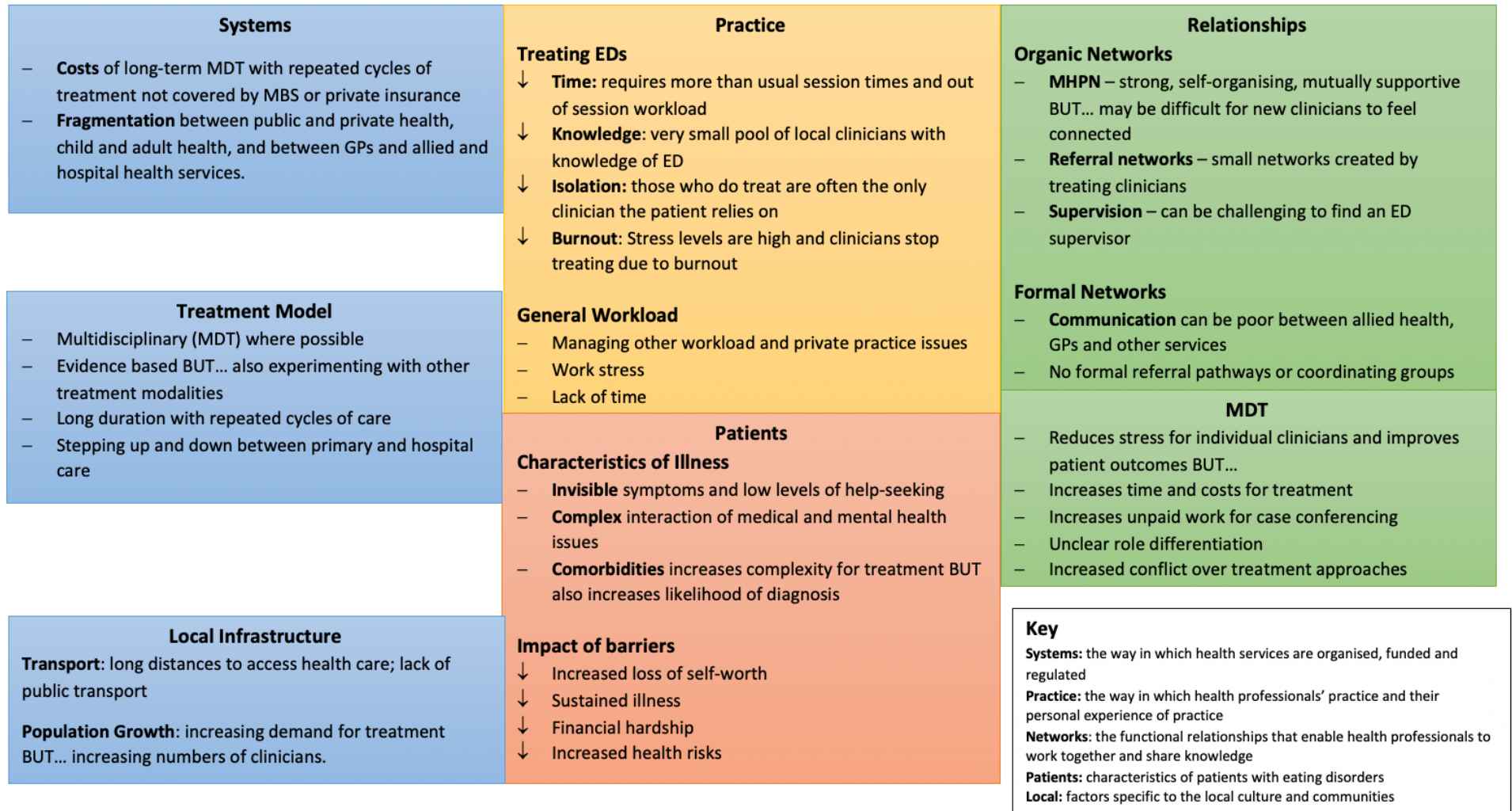
Systems

- **Costs** of long-term MDT with repeated cycles of treatment not covered by MBS or private insurance
- **Fragmentation** between public and private health, child and adult health, and between GPs and allied and hospital health services.

Treatment Model

- Multidisciplinary (MDT) where possible
- Evidence based BUT… also experimenting with other treatment modalities
- Long duration with repeated cycles of care
- Stepping up and down between primary and hospital care

Local Infrastructure

Transport: long distances to access health care; lack of public transport

Population Growth: increasing demand for treatment BUT… increasing numbers of clinicians.

Practice

Treating EDs

- ↓ **Time:** requires more than usual session times and out of session workload
- ↓ **Knowledge**: very small pool of local clinicians with knowledge of ED
- ↓ **Isolation:** those who do treat are often the only clinician the patient relies on
- ↓ **Burnout**: Stress levels are high and clinicians stop treating due to burnout

General Workload

- Managing other workload and private practice issues
- Work stress
- Lack of time

Patients

Characteristics of Illness

- **Invisible** symptoms and low levels of help-seeking
- **Complex** interaction of medical and mental health issues
- **Comorbidities** increases complexity for treatment BUT also increases likelihood of diagnosis

Impact of barriers

- ↓ Increased loss of self-worth
- ↓ Sustained illness
- ↓ Financial hardship
- ↓ Increased health risks

Relationships

Organic Networks

- **MHPN** – strong, self-organising, mutually supportive BUT… may be difficult for new clinicians to feel connected
- **Referral networks** – small networks created by treating clinicians
- **Supervision** – can be challenging to find an ED supervisor

Formal Networks

- **Communication** can be poor between allied health, GPs and other services
- No formal referral pathways or coordinating groups

MDT

- Reduces stress for individual clinicians and improves patient outcomes BUT…
- Increases time and costs for treatment
- Increases unpaid work for case conferencing
- Unclear role differentiation
- Increased conflict over treatment approaches

Key

Systems: the way in which health services are organised, funded and regulated

Practice: the way in which health professionals' practice and their personal experience of practice

Networks: the functional relationships that enable health professionals to work together and share knowledge

Patients: characteristics of patients with eating disorders

Local: factors specific to the local culture and communities

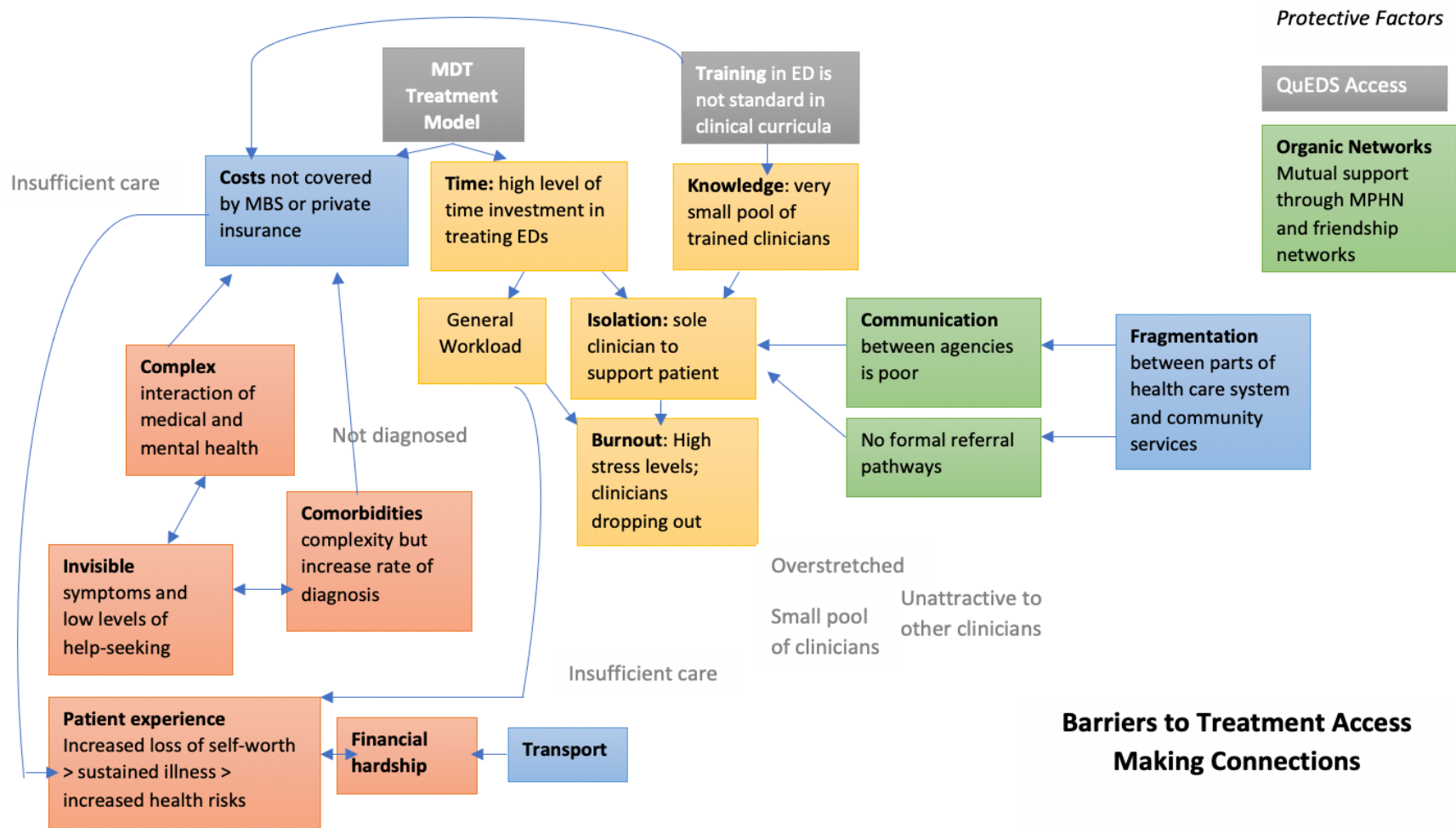*Figure 2: Service Provider Perspectives on Barriers and Facilitators to Treatment Access*

Figure3: The Connections Between Barriers to Treatment Access

1.2 The Sunshine Coast Eating Disorders Access Trial Model

Practical challenges to improving access to eating disorders treatment were investigated in regional communities through a strategy driven by the availability of Medical Benefits Scheme (MBS) rebates. The project implemented the model of care recommended to the MBS Review Taskforce (Butterfly, 2018).

The priority aims for the Sunshine Coast region were to improve access to eating disorders treatment by improving:

- Number of service providers trained to diagnose and treat eating disorders
- Rates of early identification for people with or at risk of eating disorders
- Affordability of a full course of evidence-based treatment
- Early provision of integrated multi-disciplinary treatment

Project Design

The Trial did not establish a new service model. The design developed from national practice standards defined by the National Eating Disorders Collaboration (NEDC, 2012; revised 2018) and addressed known barriers or gaps in service that could improve access. Specific interventions delivered by the Trial included:

- **Assessment:** Two assessment sessions prior to treatment decision making.
- **Screening:** Promoting evidence-based screening for GP practices and other key early identifiers.
- **Rebates**: Medical Benefits Scheme (MBS)-equivalent financial rebates for a full evidence-based course of a first line treatment.
- **Integrated Team Care**: All treatment to be delivered as part of an integrated team approach including, at a minimum, a General Practitioner (GP), mental health professional and a Dietitian.
- **Team Case Conferencing**: Rebates payable to all service providers participating in up to 6 case conference sessions per client.
- **Training:** Free professional development training delivered in the local community.
- **Central Point of Contact**: Local staff team, to improve timely access to information and support for service providers, individuals, and families. Facilitating networking between health professionals.
- **Data Collection**: Promoting the use of evidence-based tools to measure client progress and treatment outcomes.

Figure 4: The Trial Model of Support for Early Access to Treatment
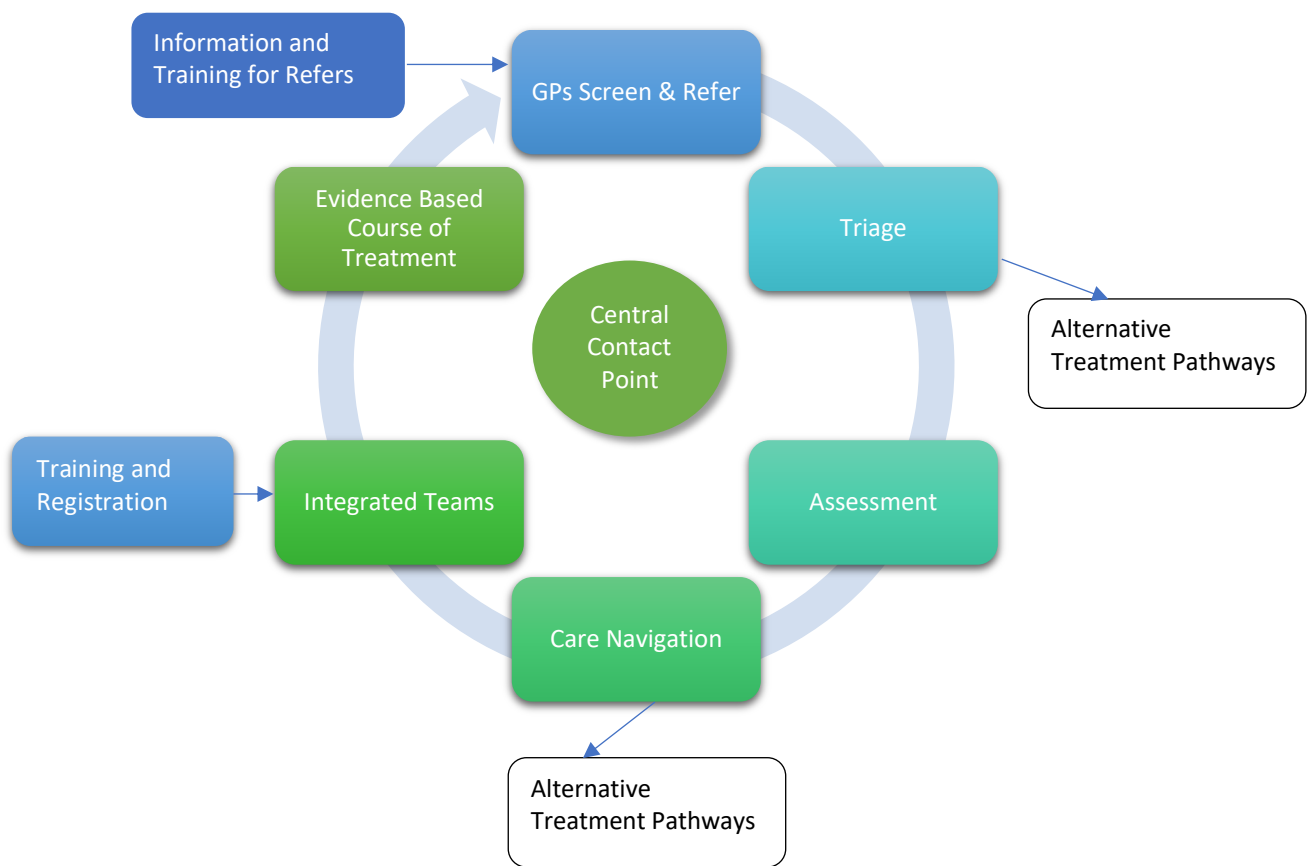
To facilitate access to low-cost integrated team care, the Trial negotiated with service providers to form teams to meet individual client needs. It also supported the creation of an eating disorder treatment team collocated with Headspace to provide screening and early intervention treatment.

Eligibility

The Trial took a transdiagnostic approach, focusing on a group of eating disorders which share a common psychopathology and common treatment approaches: anorexia nervosa, bulimia nervosa, binge eating disorder and other specified feeding and eating disorders (OSFED).

Participants were adults and young people aged over 14 years who met the DSM-5 diagnostic criteria for an eating disorder and were motivated to seek treatment.

The Trial promoted earlier access to treatment, broadly defining early intervention as meeting diagnostic criteria plus motivation to participate in treatment and one of the following:
- Duration of eating disorder symptoms less than 3 years; or
- First time seeking treatment, regardless of the duration of illness; or
- Seeking assistance to manage the risks of relapse or recurrence after previous treatment for an eating disorder.

Treatment Approaches

The treatments supported by the Trial were standard best practice, approved for use for MBS rebates.
- Guided Self-Help (GSH)
- Family Based Therapy (FBT)
- Cognitive Behavioural Therapy – Enhanced (CBT-E)
- Specialist Supportive Clinical Management (SSCM)

For dietetic care, the Trial supported the use of the RAVES Eating Model which assists individuals to develop a natural way of eating through a guided step-by-step process.

The range of treatment modalities was limited by the availability of training for service providers. Service providers who had prior education and experience in the use of other evidence-based treatments, such as Dialectical behavioural therapy (DBT), Interpersonal psychotherapy (IPT) and Focal psychodynamic therapy (FPT), were approved to use these modalities in the Trial.

Service Providers

All assessment and treatments were delivered by local health professionals in primary and allied health care. All clinical services were commissioned by the Primary Health Network (PHN) within the scope of the PHN's existing integrated stepped care approaches for mental health.

Interested service providers participated in a registration process which involved participation in an information session, provision of information on existing qualifications and experience in the treatment of eating disorders, and participation in a minimum of 13hours of further professional development training in the delivery of one or more of the specified treatment modalities.

Participants were referred for assessment and treatment by their own GP and responsibility for medical monitoring remained with the GP.

Client Intake

The Trial commenced supporting clients in February 2019. The final intake of referrals was in June 2021. The Trial had an estimated capacity to provide a full course of treatment for up to 240 clients. Capacity was determined by the availability of local service providers and budget for the payment of rebates.

One Part of a Continuum of Care

The Trial was implemented in a region that had an eating disorders outpatient service for adults (SCEDS), services for young people provided through Child and Youth Mental Health Services (CYMHS) and close enough proximity to Brisbane to access metropolitan specialist services if required. These services provided vital pathways for people in the Trial who required more intensive or specialist care than could be provided through community care. Maintaining working relationships with these services was a factor in ensuring the safety of clients in the Trial.

Implementing National Practice Standards

Good practice in the treatment of eating disorders in Australia is defined by the National Eating Disorders Collaboration National Practice Standards (NEDC, 2018), the Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines for the Treatment of Eating Disorders (Hay et al., 2014), and the ANZAED Eating Disorder Treatment Principles (Heruc, Hurst, Hart et al., 2020). All practice guides prioritise:

- **Early intervention**
  Intervention at the earliest possible opportunity is identified as essential practice. To support this, practice standards include the use of flexible entry and re-entry pathways into stepped care (NEDC, 2018) and avoidance of eligibility criteria that would restrict access based on strict definitions of severity of illness (Heruc et al., 2020).

- **Health workforce skill and knowledge**
  A skilled health workforce with the knowledge and confidence to provide evidence-based eating disorders treatment is essential for client safety and effective treatment outcomes. This is achieved through baseline training and credentialling, ongoing professional development and supervision.

- **Collaborative interdisciplinary care**
  People with eating disorders need services that are delivered by multiple disciplines, with a minimum team generally defined as a medical practitioner, a mental health professional and a dietitian if accessible. This team must work collaboratively together. When services are delivered through general primary and allied health care services strategies are required to support collaboration and coordination between service providers.

- **Care coordination**
  Coordination of services is essential to ensure consistency in treatment and minimum disruption in care when changes are required (e.g. when transitioning between levels of stepped care). People with complex needs require access to a care coordinator.

These principles informed the design of the Trial.

Modifications to the Trial Model

Uncontrolled variables are expected in real world implementation studies. The Trial has been responsive to the dynamic local and national health service environment.

Difficulties were experienced in establishing the necessary referral, triage, and invoicing systems for the Trial in a format suitable to integrate with the existing administrative processes used by service providers. A revised system was introduced in November 2019, resulting in improved engagement with service providers, however with the loss of some early data (Evaluation Progress Report, July 2019).

Introduction of new MBS item numbers for eating disorders in November 2019 represented a significant environmental change for the Trial. At that time, it was estimated that 88% of referrals to the Trial would qualify for the MBS items. This is a typical pattern of presentation for treatment where those with and a long-term illness and severe symptoms are more likely to seek help than the early intervention group the Trial aimed to recruit. From December 2019, the Trial renewed its focus on improving rates of early identification. People who were eligible for the MBS items were directed to that care pathway and were no longer accepted into the Trial.

At the same time, a need was identified for more proactive coordination and engagement of service providers, including provision of information and support for use of the new MBS items. A Care Navigation position was created, commencing in November 2019. Since that time, the care navigation role has merged with project coordination and been shared between two people.

The Trial Care Navigation Role

The Care Navigator is available to work directly with clients and with service providers with responsibility for:

- Proactively engaging and developing relationships with the PHN, service providers, community support and carer groups and referrers
- Triage and initial needs assessment, matching services to individual need and facilitating referrals identifying and addressing barriers that may prevent timely access to care
- Facilitate access to a treatment team including forming teams for that purpose
- Maintaining contact with clients to support progress in care identifying and addressing barriers that may lead to disengagement from care
- Facilitate shared problem solving to understand and resolve issues as they arise
- Respond to queries and provide information about treatment access
- Negotiate financial barriers to access to treatment (e.g. finding bulk billed services)

The two key requirements for the Care Navigation role were:

- Health professional with experience in primary and community based allied health care settings with an appreciation of the differences between community and hospital care
- Proactive and relational approach to building connections and a community of practice

No formal knowledge of eating disorders was required although a willingness to develop this was essential. It was considered important that the Care Navigator be neutral, without promoting any one approach to treatment.

Responding to Covid-19 Health Directives

The second half of the Trial has been affected by Covid-19 health directives (March 2020 to August 2021). The Trial responded by increasing access to telehealth services and by monitoring the impact on individual clients through telephone contact by the staff team.

The Covid-19 pandemic was expected to increase distress for people with eating disorders and reduce access to treatment (Vuillier, May, Greville-Harris et al., 2021). Between Nov 2020 – June 2021, 108 clients were contacted by the Care Navigator and asked about the impact of Covid-19 restrictions on their symptoms and access to treatment.

67% reported increased eating disorder symptoms and behaviours. Food insecurity, increased symptoms of depression and anxiety, financial difficulties were linked to an increase in unhealthy eating behaviours from those surveyed.

Only 30% had experienced reduced access to treatment due to the introduction of telehealth services. Reactions to telehealth sessions were varied, with most respondents preferring face to face treatment sessions.

Chapter 2: The People who Participated in the Trial

The Trial relied on local health service providers to identify people with eating disorders, refer and provide treatment within a framework of good practice standards. In total, 202 GPs and Psychiatrists referred into the Trial and 122 service providers received training and registered with the Trial to provide treatment. Trial strategies successfully developed a networked pool of knowledgeable and skilled service providers for the region.

303 referrals were received, with 215 people starting treatment through the Trial and a further 78 people receiving support to find alternative treatment options. Most clients were females aged between 14 and 67 years. More than half (65%) were young people aged under 30 years. A similar number (63.9%) were on low incomes being unemployed or students. The most frequent diagnosis was OSFED (33.5%) however, all eating disorder diagnoses were represented.

The clients who accessed treatment through the Trial had a high rate of comorbid mental health conditions (90.5%) and a variety of other life complexities including physical illness, trauma, lack of family support and financial difficulties. This complexity made a difference to how they engaged with treatment and is an important theme throughout this report. Eating disorders do not occur in isolation and access to treatment must consider the whole picture of the complexity of each person's life.

2.1 A Profile of Service Providers

The Trial has demonstrated successful and continuing engagement of service providers as both referrers and treatment providers, achieving its aim of increasing the pool of skilled service providers in the region.

A Trial goal was to recruit and train around 60 health service providers (40 mental health professionals and 20 dietitians and to contact most general practitioners in the region. At the end of the first year of operation, there were 108 service providers interacting with the Trial. Of this group, 55 were registered to provide treatment. Eighteen months later, by 30th June 2021, there were 296 service providers interacting with the Trial with 94 who had registered to provide treatment. A larger number of service providers participated in training. Stronger interest in registration in the second year of the Trial reflects the length of time required to establish a reputation and adequately engage local service providers.

- 202 GPs and Psychiatrists referred into the Trial. As a rate of service provider engagement, this compares favourably with the approximately 250 GP practices supported by the PHN in this region.

- 72 Mental health professionals including Clinical Psychologists, Registered Psychologists, and Mental Health Social Workers registered with the Trial.

- 22 Dietitians registered with the Trial.

Training and information provided by the Trial had an impact on service provider attitudes towards eating disorders:

The Trial has helped me to broaden my attitudes. I understand that eating disorders include many different presentations and not just anorexia. The most common presentation that I see is binge eating disorder and I see this as just as devastating for the client. (Dietitian)

The Trial has definitely made me more empathetic to patients of all sizes. I recognise that you don't have to be skinny. I have greater insight into overweight patients. I understand how difficult it is to be told to 'just go on a diet' when the weight issues are embedded in an eating disorder. I now have a much lower threshold for looking for an eating disorder. (GP)

This has been an eye-opening experience. Eating disorders are much more common that you think. It affects everybody in some way. It's almost like a fog; disordered eating is so common that we cannot see what is really happening. (Dietitian)

2.2 Clients Registered with the Trial

The first intake of clients in 2019 included people with eating disorder symptoms ranging from sub-clinical to very severe and chronic full-syndrome disorders. In November 2019, 9 months after the first intake of clients into the Trial, new MBS item numbers were introduced for people with severe or complex presentations of an eating disorder. From that date, people who were eligible for the MBS Eating Disorders Treatment Plan were no longer eligible for the Trial. This included most people with anorexia nervosa.

Around 13 to 14 referrals were received each month, except during the summer holiday period. In total, 303 individuals were referred to the Trial, with 215 proceeding to treatment through the Trial received treatment. 29% of referrals did not progress into the Trial; of this group, 78 individuals were assisted to access an alternative treatment pathway (e.g. MBS or hospital outpatient program). In addition, 10 referrals were not eligible for the Trial or alternative treatment due to factors such as their age (under 14 years), geographic location or primary diagnosis.

Figure 5: Referrals into the Trial
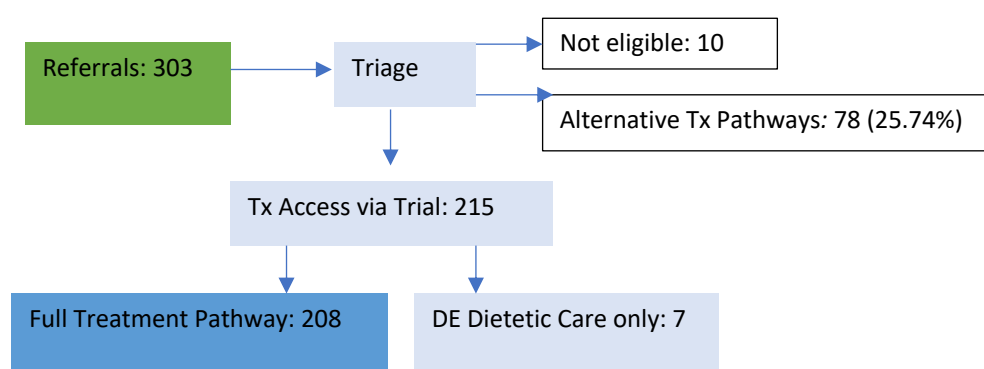
Drop Out during Treatment: 25 (11.63%)
Note that this rate only refers to people leaving treatment and not the full dropout rate from the Trial

By 18 August 2021, 179 clients had completed treatment or otherwise left the Trial. Thirty-four clients were still receiving treatment. Late referrals where the client was not able to complete a course of treatment by August 2021 were not included in the data for analysis.

Most clients were female with 64.96% in the age range for the onset of an eating disorder, between adolescence and young adult. However, clients aged over 40 years included many of the presentations of binge eating disorder. These are people who have had an undetected eating disorder for many years and who are now experiencing the physical health consequences including gastrointestinal disorders and obesity related conditions. At least 63.9% of clients may be assumed to be on low incomes as they were students or unemployed; an additional 3.4% were retired.

The most common eating disorders are Other Specified Feeding and Eating Disorders (OSFED) and binge eating disorder, with lower levels of prevalence of bulimia nervosa and anorexia nervosa (Galmiche, Dechelotte, Lambert and Tavolacci, 2019). In the Trial, the occurrence of OSFED was high

at 33.5% of all referrals, however, the rate of binge eating disorder was relatively low (13.6%) when compared to a rate of 17.6% for anorexia nervosa and 19.0% for bulimia nervosa.

Table 3: Baseline Characteristics of Sample (active and closed referrals)*

Data Field	Categories	Trial Participants
Gender	Female: 209 (94.6%)	
Diagnosis	Anorexia nervosa Bulimia nervosa Binge eating disorder Other (OSFED) ARFID Insufficient information	39 (17.6%) 42 (19.0%) 30 (13.6%) 74 (33.5%) 2 (0.9%) 34 (15.4%)
Age (N = 219)	Mean 27.04 years (SD 13.73)	Range 14 years to 67.7 years 34.7% aged between 14 and 18 years.
Duration of Illness (N = 150)	Mean 5.28 years (SD 7.12)	Range 0 – 32 years
Previous Treatment (N = 217)	65 (30%)	
Comorbidities	Comorbid mental health condition	90.5%
Occupation (N = 205)	Unemployed Employed Student Retired	34 (17.1) 67 (32.7%) 96 (46.8%) 7 (3.4%)

* Active and closed referrals includes a small number of cases who were eventually redirected to an alternative treatment path.

Complex Presentations in Early Intervention

People with any eating disorder are more likely than those without an eating disorder to develop a comorbid psychiatric diagnosis (Hay et al., 2014). Approximately 55% - 97% of people diagnosed with an eating disorder have another mental illness (NEDC, 2017). People referred to the Trial had high rates of mental health comorbidities, physical health issues and psychosocial challenges. Ninety percent (90.5%) had an identified comorbid mental health condition, placing this cohort at the high end of the expected range.

Many participants experienced multiple physical and mental health challenges illustrated by this description of an individual client from case notes: *Client referred with Bulimia Nervosa, severe anxiety, Post Traumatic Stress Disorder, Borderline Personality Disorder, and current alcohol dependence. Financial hardship identified.*

Table 4: Comorbidities Experienced by Trial Clients

Presence of comorbidity at baseline	No.	% *	Research benchmark
Anxiety	168	76.0%	64% of people with an eating disorder experience an anxiety disorder (Kaye, Bulik et al., 2004)
Depression	116	52.5%	45% to 86% of individuals with an eating disorder experience depression (O'Brien and Vincent, 2003).
Stress / Bullying	30	13.6%	
PTSD	18	8.1%	
OCD	9	4.1%	OCD commonly co-occurs with eating disorders (Blinder et al., 2006; Simpson, Wetterneck et al., 2013).
Bipolar disorder	7	3.2%	
Borderline Personality Disorder	4	1.8%	Approximately 58% of individuals with eating disorders have a comorbid personality disorder (APA, 2013). BPD is one of the most common personality disorders to cooccur with eating disorders (Wisniewski and Anderson, 2018).
Substance misuse	3	1.4%	30% of people with an eating disorder will experience substance abuse. (APA, 2013).
Schizophrenia	1	0.5%	
Other not specified	21	9.05%	
Any Comorbidity	200	90.5%	

* Note: Clients frequently presented with more than one comorbidity

Comorbidity is only one part of complexity. Trial clients were also affected by a range of psychosocial factors (e.g. lack of family support or care-giving responsibilities) financial limitations, and associated issues with food insecurity, medical health issues and previous trauma (e.g. sexual assault). These have all been associated with poor treatment outcomes (Abbate-Daga, Amianto, Delsedime et al., 2013).

Clients are often distressed or have very complex life circumstances, including financial issues and family relationship challenges. There is often a history of trauma. You need to deal with the eating disorder in that bigger context. (Service Provider)

Complexity is a recurrent theme in all the issues discussed in this report, having an impact on the duration of treatment, use of adjunctive treatments and the need for low-cost services.

The Trial was excellent. For the first time I've really been able to see a correlation between the triggers of my ED symptoms occurring in my early teens and how food affected my body. I now, at the age of 56 understand how food makes me feel physically and emotionally and how I have used food to feel in control or comfort me when I'm sad or depressed. I have been able to make different choices now which has improved my physical health significantly. I now choose to eat regularly because I know this is what will keep me well physically and mentally. How I view myself and my body has also changed for the better. For the first time in my life, I am learning how to care and nurture my body. The Psychologist and Dietitian were fantastic. They both gave me such good practical tools and I felt safe and heard. The Care Navigator was so supportive in negotiating gap free clinicians. She knew being on a pension meant I didn't have the money to afford any gap. I wouldn't have known how to go about this. She gave me confidence to keep going and remain engaged. I am so grateful for this experience and wish for everyone to have the opportunity to get this kind of support.
(Client Exit Interview)

The process is challenging. I went every week and it is hard when you go into therapy as you have to trust the process and there is nowhere to run. It was very challenging but I really wanted to keep going. I had been struggling for 10 to 15 years and this was the first time that someone was able to give me what I needed. I felt so blessed to receive the right help. I wanted a future without an eating disorder and with the right help and the right support, it is achievable. (Client Exit Interview)

Chapter 3: Safe and Effective Treatment

Access to treatment is only of benefit if that treatment is safe and effective. Using remission of eating disorder symptoms as a measure of treatment outcomes, between 54.5% and 61.2% of clients in the Trial achieved ED15 scores consistent with normal patterns in the community.

For clients receiving early intervention, the degree of change was small but comparable with other studies of early intervention. For those who started the Trial with a higher level of clinical severity, the level of change compared favourably with the outcomes of eating disorder research trials.

The Trial found that facilitating access to treatment delivered by non-specialist service providers in the community was safe and effective for people with lower levels of severity of eating disorder when service providers had access to training and professional support. Pathways to specialised eating disorder treatment services were essential providing stepped care for those with more severe illness.

3.1 Effects of treatment

Eating disorders are marked by patterns of distorted cognition, particularly in relation to food and body image, which directly influence the disordered eating and compensatory behaviours (bingeing, purging, fasting) that are characteristic of an eating disorder (Legenbauer, Radix, Augustat and Schutt-Stromel, 2018). The effect of treatment in the Trial was measured in two ways: (1) degree of improvement in eating disorder cognitions and (2) the percentage of clients reaching remission, defined as reaching normative levels of eating disorder cognition scores together with an absence of any eating disorder behaviour.

Data is presented for Trial clients for whom ED15 data was available: (1) the group who started treatment (Intent to treat sample, ITT; N = 157) and (2) the group who completed treatment (completers; N = 106). Completion was defined as either the client and service provider mutually agreeing that the client was ready to end treatment, or the client had discontinued treatment after 10 or more sessions with a decrease in eating disorder symptoms.

To interpret the effects of Trial treatment, we benchmarked these against clinical research trials evaluating eating disorder treatment. Normative classification of eating disorder cognitions is commonly based on EDE-Q ≤2.77 (within 1 SD of norms; Mond, Hay, Rodgers and Owen, 2006). 2006). In our sample, EDE-Q data was not systematically collected by community clinicians, so we utilised the sessional ED15 global score, which correlates highly ($r = 0.89$) with the EDE-Q, and has normative levels defined as ≤ 3.38 (within 1 SD of norms; Tatham et al., 2015). To accommodate variations in service provider usage of the ED15, first and last ED15 scores were used.

Remission Status

As the Trial promoted early detection and access to treatment, it was expected that baseline scores (levels of ED cognitions, presence of eating disorder behaviours) might be lower than the clinical samples in published studies. Between 38.5% (ITT group) and 43.7% (completer sample) had normative baseline ED15 cognitions scores. Data is presented for the whole client sample and for a subsample of participants (ITT sample, N = 76; completers N = 50) who met clinical criteria at baseline, defined as having an ED15 score >3.38 and presence of at least one compensatory behaviour.

Consistent with the characteristics of an early intervention group, a range of Trial participants started with normative data for either eating disorder behaviours, eating disorder cognitions or both (Table 5). Post treatment, there was a significant increase in those reaching normative scores for eating disorders. Overall, 61.2% (completers) and 54.5% (intent-to-treat) had normative final scores on ED15 together with no eating disorder behaviours.

Of those who reported at least one ED behaviour or clinical levels of ED cognitions at baseline, 42.7% (completers) and 37.1% (intent-to-treat) had moved to normative scores for both at post-intervention. Our rates of remission are in line with clinical research studies, where remission rates

range from 31.0-90.6% (completer samples) and 28-63.5% (intent-to-treat samples; Pellizzer et al., 2019).

Table 5: Remission Rates

	Completers N = 103	ITT sample N = 143
Baseline		
No ED behaviours	27 (26.2%)	37 (25.9%)
ED cognitions score in normal range	45 (43.7%)	55 (38.5%)
Both criteria normative	19 (18.4%)	25 (17.5%)
Post intervention		
No ED behaviours	70 (68.0%)	89 (62.2%)
ED cognitions score in normal range	82 (79.6%)	100 (69.9%)
Both criteria normative	63 (61.2%)	78 (54.5%)
Moved to normative (ED cognitions, behaviour) post intervention	44 (42.7%)	53 (37.1%)

The sample group for data analysis included 22 clients who were underweight. Of this small group, 8 achieved a normative BMI classification by the end of treatment, with the remaining 14 clients reporting varying levels of progress.

Trial participants showed significant improvement in eating disorder cognition scores in both completer and intent-to-treat samples (Table 6). The moderate to large effect sizes (Cohen's *d* = 0.7-0.91) are comparable to a recent evaluation of an early intervention initiative in Australia (*d* = 0.45; Radunz, Pritchard, Steen et al., 2021).

Table 6: Pre- and post-treatment Effect Sizes for ED Cognitions (ED15)

Completers			
Variable	Whole sample (*N* = 69)		
	Pre M *(SD)*	Post M *(SD)*	Effect size *(95% CI)*
ED15 cognitions score	3.47 (1.49)	2.10 (1.51)	0.91 (.63,1.20) *
Intent to Treat Sample			
Variable	Whole sample (*N* = 102)		
	Pre M *(SD)*	Post M *(SD)*	Effect size *(95% CI)*
ED15 cognitions score	3.53 (1.41)	2.40 (1.62)	0.74 (.50,.98) *

*Significant; Effect size = Cohen's *d*, where 0.2= small, 0.5= moderate, 0.8=large (Cohen, 1988)

Across 16 published effectiveness studies targeting eating disorders, Cohen's d effect sizes for eating disorder cognitions ranged from 1.5 – 2.37 (completer samples) and 0.61-2.29 (Intent to treat samples; Pellizzer et al., 2019). In order to benchmark our results against these trials in clinical populations, Table 7shows our results for the subsample of clients who met clinical criteria at baseline. Results in the current study with upskilled community clinicians were comparable to those obtained in eating disorder research trials.

Table 7: Pre- and post-treatment Effect Sizes: Subsample with clinical levels at baseline

Completers (Clinical Criteria at Baseline)			
Variable	Whole sample (*N* = 31)		
	Pre M *(SD)*	Post M *(SD)*	Effect size *(95% CI)*
ED15 cognitions score	4.57 (0.76)	2.70 (1.52)	1.56 (1.11,2,00) *
Intent to Treat Sample (Clinical Criteria at Baseline)			
Variable	Whole sample (*N* = 53)		
	Pre M *(SD)*	Post M *(SD)*	Effect size *(95% CI)*
ED15 cognitions score	4.47 (0.72)	3.09 (1.61)	1.09 (.75,1.43) *

*significant improvement; Effect size = Cohen's *d*, where 0.2= small, 0.5= moderate, 0.8=large (Cohen, 1988)

Factors affecting rate of change (moderators)

Duration of illness pre-treatment did not impact on the rate of improvement over time, nor did having received previous treatment for an eating disorder. Improvement in eating disorder cognitions was moderated by several factors, including the client's weight classification. While progress was steady for non-underweight service users (BMI≥18.5), this started to rebound for underweight participants.

*Graph 1: Progress in treatment for underweight and non-underweight clients*
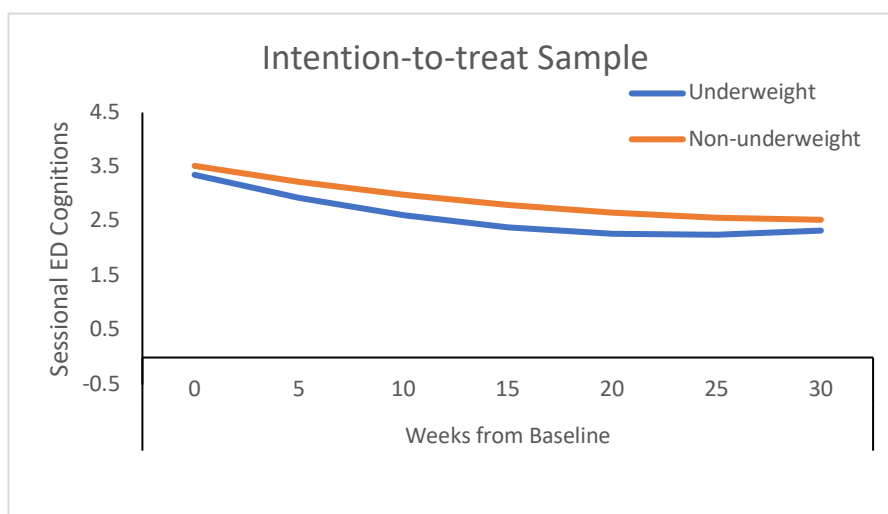
It has been suggested (Fairburn, 2008) that as clients with anorexia nervosa put on weight, their dissatisfaction with their body becomes stronger. This aspect can take longer to treat as they habituate to a new body and may explain why relapse is common in this population, especially if treatment finishes too early and does not have a focus on acceptance of the new body.

The Trial found that the presence of comorbidities slowed the initial rate of response to treatment compared to clients with no comorbidities, however this former group caught up with the progress of the latter around session 30 (for those who received a longer course of treatment). A longer course of treatment is likely to be a factor in helping clients with comorbidities to reduce their eating disorder symptoms. Comorbidity does not make a difference to the final outcomes of treatment and should therefore not be used to determine eligibility for services.

Graph 2: Influence of comorbidities on progress in treatment
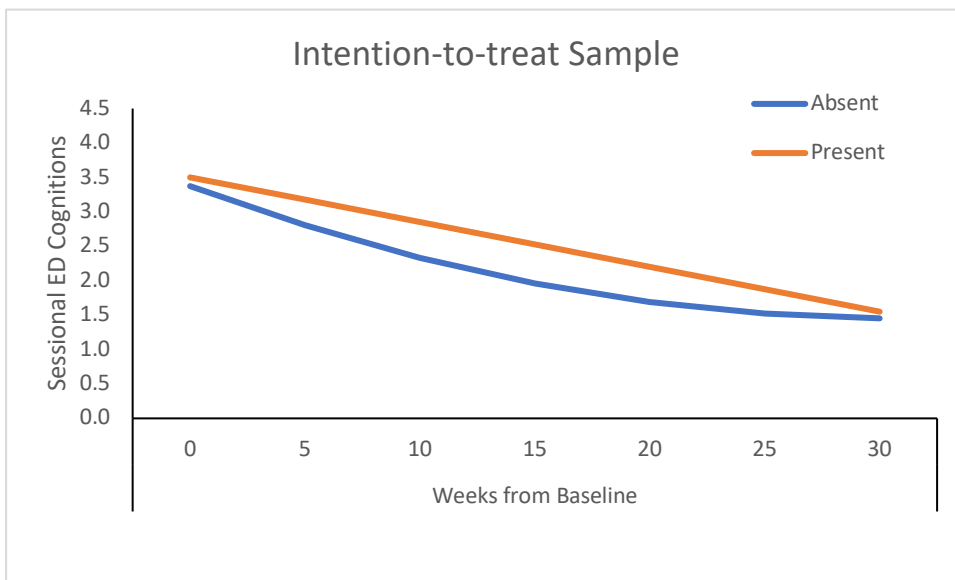
3.2 Completing Treatment

A client needs to complete a course of treatment that is sufficient to achieve their treatment goals. By August 2021, 106 clients (72.0%) had completed treatment from a sample of 157. Completion rates were near identical for those who were underweight (71.0%) and non-underweight (72.3%) at baseline. These completion rates compare favourably with the 59.9% completion rate found in a study of CBT-E and FBT delivered in a routine clinical setting (Mountford, Allen, Tchanturia et al., 2021). Only 17.5% voluntarily withdrew from treatment.

Table 8: Treatment Retention and Dropout Rates

Client Status	Number	%
Completed treatment or exited after achievement of goals	103	72.0%
Transferred to alternative treatment pathway (MBS)	15	10.5%
Voluntarily left treatment without achieving goals	25	17.5%
Total Sample	143	100%

Leaving treatment prematurely is common for people with eating disorders (DeJong, Broadbent, and Schmidt, 2012). Estimates of premature termination of treatment vary between 29% and 73% (Fassino, Piero, Tomba et al., 2009). DeJong and colleagues (2012) defined a range between 20% and 40%, although other studies have identified an average dropout rate of approximately 50% of clients (Vinchenzo et al., 2021). Within these ranges, the Trial experienced a low rate of premature withdrawal from treatment.

Defining Premature Withdrawal from Treatment

Experiences of eating disorders and recovery are diverse and there is a wide range in the length and intensity of treatment required to achieve sustainable remission of eating disorder symptoms (Heruc et al., 2020). The duration of treatment cannot be determined before the client commences treatment.

Intervention dosage is the number of treatment sessions that are most likely to be needed to achieve treatment goals, based on clinical research. For the most commonly used treatments (e.g. CBT-E, Specialist Supportive Clinical Management) the recommended intervention dosage is 20 sessions for people with bulimia nervosa or binge eating disorder. People with anorexia nervosa are expected to require a longer course of treatment up to 40 sessions, in order to restore nutritional status and sustain weight gain (NEDC, 2012). The longer course of eating disorder treatment is required to achieve sustainable remission of symptoms.

Treatment of less than 10 sessions is not currently supported by evidence. Nine clients left at or before session 10 with improvement in eating disorder symptoms. Of this group, only two withdrew from treatment, with the other seven transferring to an alternative treatment pathway. Most clients required between 15 and 30 sessions of treatment. Withdrawal from treatment prior to session 10 may indicate that treatment was ineffective in engaging the client and supporting early progress in symptom remission.

Premature withdrawal from treatment is associated with poor health outcomes, and a high risk of relapse (Karekla, Konstantinou, Ioannou et al., 2019; Vinchenzo, McCombie and Lawrence, 2021). Treatment for eating disorders is cost-effective when it is provided early in the course of illness and when people complete the full course of treatment. Premature withdrawal from treatment decreases cost effectiveness (Le, Barendregt, Hay et al., 2017).

Definitions of premature withdrawal from treatment vary depending on the context, with differences between research studies and real-world clinical settings. The Trial defined premature withdrawal from treatment as cessation of sessions at or before session 10 in the absence of collaborative agreement between the client and the clinician.

Making the Decision to Persist in Treatment

Much of the research into premature withdrawal from treatment for eating disorders has focussed on characteristics of the disorder (Bandini, Antonelli, Moretti et al., 2006). The ego-syntonic nature of eating disorders (Vitousek, Watson and Wilson, 1998), the binge-purging subtype of anorexia nervosa, specific psychological traits, (Fassino et al., 2009) and the experience of intense shame and self-blame (Petersson, Birgegard, Brudin et al., 2021) are all associated with dropout from treatment.

Developing improved understanding of dropout from treatment for eating disorders is important. Personal characteristics are not amenable to direct change by clinicians or the health system. There is a need to identify clinical practices that can moderate client decisions to engage and persist in treatment. The onus is then on the treatment provider and health system to present treatment in ways that appear less threatening and more hopeful.

Many people with an eating disorder find the process of change difficult (Heruc et al., 2020). There is an inner conflict (Vinchenzo et al., 2021) described by one author as '*a pervasive pushing-pulling dynamic*' (Gamberg, 2015) which influences decision making throughout treatment and recovery. The decision to drop out from treatment could be framed as a functional response that helps the client to feel safe and in control. When withdrawing from treatment, the client is weighing the perceived risks, rewards, and consequences of persisting in treatment. People generally are more likely to choose to maintain their current status than seek change, especially when there is an element of risk or uncertainty about the outcomes of the decision (Alos-Ferrer, Hugelschafer and Li, 2016; Sautua, 2017).

Factors that Influence Decisions about Treatment

Clinicians working with the Trial had access to a range of supports designed to encourage the delivery of evidence-based treatment. We hypothesise that these supports played a role in reducing the rate of dropout. The Trial Care Navigator provided active follow-up of people who had missed treatment sessions or otherwise indicated that they were thinking about withdrawing. Decisions were being made based on highly individual personal life factors, however four consistent factors emerged that appear to influence the decision to withdraw from treatment, illustrated in figure 6 below.

Figure 6: Factors contributing to client decisions about treatment
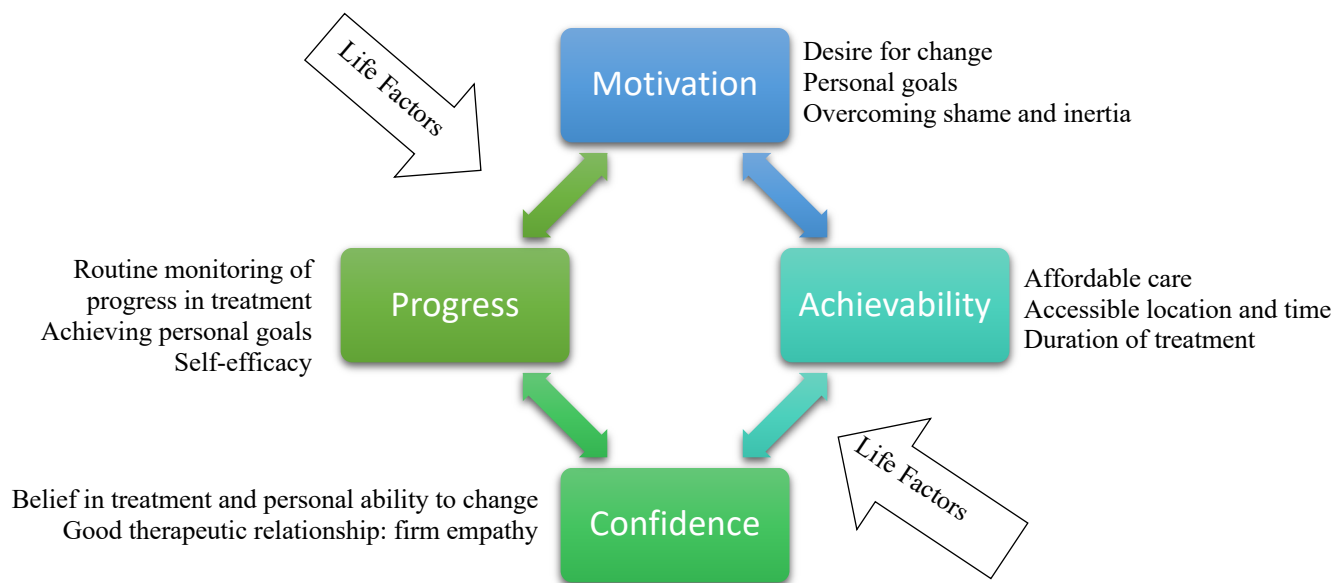
Motivation, the factor that guides and maintains goal-oriented behaviour, is a key factor in predicting treatment outcomes and rates of dropout from treatment (Vall and Wade, 2015). Change in eating disorder behaviour can lead to increased anxiety, reducing motivation and prompting withdrawal. Working with the client on motivation and confidence to succeed early in treatment can be beneficial (Steele, Bergin and Wade, 2010).

The Trial found that motivation was not a consistent state; it fluctuated in response to the experience of change:

> *There have been times when I was really motivated but then ED brain fights back so it has moved back and forth between the two different states. (Care Navigation Case Files)*

> *I am glad I stayed with the Trial. Initially ED symptoms got worse, however the team explained this was to be expected and gave me strategies to persevere and better understand what and why I was behaving like this. (Care Navigation Files)*

> *I feel like without the program I would not have been able to progress as far as I have and I am really grateful for that. There were a couple of sessions where I felt that things weren't going where I thought they would. A couple of times I was in tears and felt like a failure. My psychologist helped me to see what I was achieving and I think that made all the difference. (Care Navigation Case Files)*

Motivation was not solely influenced by the experience of illness and personal change. Where clients provided reasons for considering leaving treatment, these included practical considerations which were weighed against the perception of making progress in treatment. Practical risks reported by clients in the Trial included the financial costs of treatment, the impact of attending sessions on ability to work or study, and relationship difficulties; these are consistent with factors identified in other studies (e.g. Vinchenzo et al., 2021).

The Impact of Time Delays Between Referral and Treatment

The level of motivation at the point of referral may not be sustained over an extended waiting period before treatment. Waiting times are one key factor in dropout before starting treatment (Kastner, Weigel, Buchholz et al., 2021) with longer waiting times associated with poorer long term health outcomes (Byrne et al., 2011; Fursland, Erceg-Hurn, Byrne and McEvoy, 2018). The Trial's triage process reduced waiting times to an average of two weeks, which may have reduced the rate of dropout between referral and starting treatment.

A real value add from the Trial has been being able to have someone contact the client within 48 hours of the referral being made. This means that we can engage with people when they are ready. If you have to wait for months then the critical moment is lost. (Service Provider)

The Ability to Get to Appointments

The duration of treatment and associated costs emerged as the two most common challenges in making the decision to persist in treatment. Briefer courses of mental health treatment tend to have lower rates of withdrawal (Ogrodniczuk, Joyce, and Piper, 2005). Eating disorder treatment is intense, multi-disciplinary and often of long-duration and this is reflected in the costs of treatment (Weissman and Rosselli, 2017). The duration of treatment represents a serious disruption to usual activities, a high cost in gap payments, plus the hard and uncomfortable work of therapy.

More than half (63.9%) of Trial clients were on low incomes and negotiated low-gap and bulk billed services were essential to enable these clients to access a full course of treatment. Intense feelings of shame are part of the experience of an eating disorder (Cook and Morgan, 2017) and this is associated with reluctance to share information with treatment providers (Swan and Andrews, 2003). Trial Care Navigation records demonstrate that clients were often too ashamed to mention issues to their service provider such as their inability to pay for services.

Even with the reduction in fees, it is still hard to keep going as it is still a lump sum coming out each week. There is also a psychological element that is a barrier as you don't feel that you deserve the support and when paying is a struggle, you doubt yourself and your worth in pursing the process.
(Care Navigation Files)

I don't want to ask about gap, as don't want to disadvantage myself by seeming unwilling to pay.
(Care Navigation Files)

Care navigation support, with active follow-up of people who were considering leaving treatment, was identified by clients and service providers as an important factor in supporting retention in treatment, helping to resolve the 'push-pull' dilemma. This helped people to identify their reasons for withdrawing and negotiate practical solutions outside the therapy session. The combination of access to rebates, gap-free services and care navigation was vital for most of the clients in the Trial.

These strategies were practical in the developed coastal area of the Sunshine Coast region. For the rural communities around Gympie, there were few clinicians available to provide eating disorders treatment. The necessity to travel to appointments and the high level of complexity experienced by each client contributed to an increased dropout rate. For the small subsample from this area, there was a 40% dropout rate. This is still within the expected range for eating disorders treatment but higher than the Trial overall. Care Navigation was still successful in supporting those who did complete treatment however the resources available to the Care Navigator were limited.

Confidence in the Treatment

Client confidence in treatment was associated with their relationship with the service provider, their understanding of the treatment to be provided and their perception of progress. The Trial modified two factors to improve confidence: the service provider knowledge and skill, and the communication between service providers.

A multi-disciplinary approach to eating disorders treatment requires strong relationships and frequent communication between service providers (Hay et al., 2014). As discussed in Chapter 4, the Trial found having a dietitian in the treatment team (3 or more sessions) and case conferencing between team members (2 or more times over the course of treatment) improved rates of treatment completion.

Clear early symptom reduction contributes to a positive therapeutic alliance (Graves, Tabri, Thompson-Brenner et al., 2017). (Clinical standards support 'session by session evaluation' of progress (Heruc et al, 2020). Trial protocols required clinicians to use a validated measure of client progress (ED15) at each session and to routinely weigh the client. While this was implemented for data-collection purposes, it has emerged as a predictor of treatment retention and outcomes.

Active management of waiting lists and follow-up of clients during treatment contributed to a low dropout rate for the Trial. Once the client was engaged in treatment, the Trial found that measuring progress in treatment, reducing out-of-pocket expenses, and integrated team care addressed the practical concerns that contributed to premature withdrawal from treatment.

Chapter 4: Improving Treatment Outcomes

Some factors in the way that treatment is delivered are likely to strengthen or reduce the impact of that treatment. Trial practices and data were analysed to identify any activities that play a significant role in improving treatment outcomes.

The client outcomes of the Trial were achieved through a cohort of trained and registered service providers. This was essential to meet the national competency standards for eating disorders and match the requirements for MBS eating disorder item numbers.

In addition to this essential knowledge of treatment approaches, the Trial found that accuracy of diagnosis made a difference to treatment access and the use of core eating disorder treatment practices made a difference to treatment outcomes. Regular use of validated tools (e.g. ED15) to measure progress in treatment and regular weighing emerged as important practices that make a difference to the effectiveness of treatment.

Integrated team care also played an important role in improving treatment outcomes. The Trial supported integrated care through the payment of rebates for team case conference sessions. Trial results demonstrate that regular case conferencing improves treatment outcomes.

This chapter provides details of the Trial's training program and identifies core treatment practices that may be helpful to support review of client progress through MBS eating disorder treatment plans. Discussion also includes consideration of the lived experience perspective on effective treatment.

4.1 Training and Credentialing

People with eating disorders are reliant on the skills of health professionals to identify the eating disorder and to help them engage with treatment and be motivated for change. Skill and knowledge to treat eating disorders are associated with better treatment outcomes (Heruc et al., 2020).

Limited understanding of eating disorders (Walker and Lloyd, 2011) and lack of confidence to diagnose and treat eating disorders (Cadwallader, Godart, Chastang et al., 2016) affects access to treatment. A recent Australian study found that 73% of clinicians in a regional health service had little or no confidence to work with clients with eating disorders, with a strong correlation between training and confidence to treat (Lakeman and McIntosh, 2018).

Improving access to training and opportunities for ongoing professional development for health professionals therefore provides a strategy to improve access and quality of treatment (Fitzsimmons- Craft and Wilfley, 2019). The Medicare Review Taskforce Eating Disorders Working Group (MBS, 2018: pp 9-10) recommended further support and education for GPs, the development of training and clinical guidance for allied health professionals, and development of a national credentialling process.

The influence of training on treatment access was a broad theme in the Trial's Delphi study with insufficient access to training at undergraduate level and in professional specialisations identified as a barrier. Inclusion of training in mental health and eating disorders was recommended for all medical professionals together with inclusion of eating disorder treatment as a core competency for psychologists.

The client outcomes of the Trial were achieved through a cohort of trained and registered service providers. An expression of interest process collected the details of service providers prior to registration, including their existing levels of experience and training in eating disorders. All service providers were required to participate in a minimum of 13 hours training delivered through the Trial, comprising a three-hour introductory session with an emphasis on assessment and diagnosis and at least 10 hours of training in a relevant treatment modality.

A training suite of 5 standalone workshops was developed to provide a stepped suite of learning modules totalling 65 hours of training. Training modules included all the treatment modalities approved for delivery through the Trial (FBT, CBT-E, GSH, SSCM). All training workshops were delivered by experts in the relevant treatment modalities and were provided free of charge. Two additional workshops were developed as extension learning, in response to local needs: '*Eating Disorders in the Larger Body'*; and '*The Art and Science of CBT-E in Practice'*, which focused on the practical challenges of delivering CBT-E in the private practice setting.

Satisfaction with workshop content was consistently high with an overall satisfaction rating across all workshops of 2.71 (mean rating calculated on a range of 0 low to 3 high). Participants were primarily allied health practitioners. Workshops attracted a mix of eating-disorder experienced clinicians and those who had little previous experience in this field.

Table 9: Training Workshops

Training Workshops	Duration
Intro to Assessment, Treatment & Management of ED's	3 Hours
CBT-E - Manualised Therapy	16 hours
Guided Self-help - Manualised Therapy	4 Hours
Eating Disorders in the Larger Body	3 Hours
Family Based Therapy	14 hours
Specialist Supportive Clinical Management (SSCM)	14 Hours
The Art and Science of CBT-E in Practice	7 Hours
Introduction to Child & Adolescent Eating Disorders	4 Hours
	65 Hours

Training was initially planned for the first year of the Trial, however, in response to locally identified needs, further training sessions were delivered in CBT-E and FBT at the beginning of 2020 and an online micro-skills training program was introduced from October 2020. Five free workshops were presented via videoconferencing. The focus for these workshops was on micro features of good practice selected to address specific practice issues identified in the Interim Evaluation of the Trial.

Micro skills Workshops
- Making an informed diagnosis.
- Setting up non-negotiables of therapy.
- Using collaborative open weighing or blind weighing techniques.
- Why FBT? -Understand why, when, where using FBT is recommended as treatment of choice.
- Common challenges in implementing FBT – How to rally family and keep them engaged.

The free training has been really worthwhile. We particularly appreciated the online micro-skills training on specific issues like how to diagnose. Having the information in training directly linked to local data and issues that we are all experiencing in our practices made the topics very relevant (Training Evaluation Feedback)

The format of locally delivered and online workshops attracted strong rates of participation, including service providers who attended multiple training sessions throughout the Trial. The Trial did not provide access to supervision. The combination of monitoring client data and targeting micro-skills training to address issues as they arose with support for peer case conferencing may have gone some way to filling this gap. The strategy warrants further investigation in areas where there is limited access to skilled supervision in eating disorders treatment.

The high level of interest in training and in registration with the Trial reflect a proactive engagement strategy that connected with individual service providers and went some way to addressing the reasons they may not have been treating eating disorders before. Motivation for engagement in the Trial included gaining access to rebates (prior to the introduction of MBS items), free training, and being connected into a supported community of practice in the local region.

4.2 Securing a Helpful Diagnosis

GPs and other health service providers find diagnosing eating disorders challenging (Johns, Taylor, John, and Tan, 2019; Marks, Beaumont, and Laird Birmingham, 2003). Some service providers in the Trial have experienced difficulties making an initial diagnosis, particularly when different eating disorders have similar presentations e.g. ARFID and anorexia nervosa both present with low body weight; anorexia binge purge type and bulimia nervosa are both characterised by binge purge behaviours.

Slightly more than half (54.8%) of clients who met the criteria for anorexia nervosa were accurately identified at referral. Of greatest concern was the 14 clients with a BMI less than 18.5 who were not identified as possible presentations of anorexia nervosa. Suspected diagnoses for this group included binge eating disorder, bulimia nervosa, OSFED and two were referred for investigation of disordered eating. Conversely, 22 cases were initially identified by the service provider as having anorexia nervosa when their BMI was greater than 19. The accuracy of diagnosis of binge eating disorder was greater with 75.9% of possible cases correctly identified. The diagnosis of OSFED seemed to cause greatest confusion, with only 40% of cases with this initial diagnosis eventually meeting diagnostic criteria. Diagnoses for the remaining 60% were found to include anorexia nervosa, ARFID and bulimia nervosa.

A clear diagnosis often does not emerge until the psychologist has fully assessed the client. It takes time to build rapport with the client and work through the many steps in assessment. Premature diagnosis risks referring the client to an inappropriate treatment pathway. The important exception is for underweight participants (BMI<18.5) where medical tests may be required immediately for client safety and management.

We are concerned about people being labelled with a diagnosis too early in the referral process. Some people are being told they have ARFID. Later on, it emerges that they have Anorexia Nervosa and qualify for an Eating Disorder Plan. You really need two or three sessions for a full mental health, medical and dietetic assessment before clients are identified as eligible or not eligible for rebates. (Service Provider)

Assessment of an eating disorder is a skilled process requiring two to three sessions to complete. Eating disorder plans should not be put in place until after assessment. This leaves people in a difficult position of they cannot self-fund the assessment process. (Service Provider)

Diagnosis is made more difficult by the presence of comorbidities. Assessment of an eating disorder should include identification of comorbid conditions and assessment of the clinical severity and medical risk associated with each condition to identify which condition should be prioritised for treatment (NICE, 2019).

The Trial adopted two strategies to help improve the accuracy of diagnosis:

- Additional micro skills training was provided in 2021 on assessing eating disorders and this was well received. However, feedback indicated that more is required.

- Two assessment sessions were made available on GP referral for suspected disordered eating, without an eating disorder diagnosis. This approach has encouraged early intervention without prematurely labelling clients with a specific diagnosis

4.3 Evidence Based Treatment

Consistent delivery of evidence-based treatments is expected to improve rates of remission. It is also important to know what type of therapy works or has not worked for the individual client when planning further treatment.

Evidence-based treatment is sometimes equated with the treatment modality with the highest level of research evidence supporting efficacy. In practice, enabling the client to experience and benefit from evidence-based treatment is more nuanced. The framework for the Trial combined national clinical practice standards with treatment modalities supported by research. The treatment delivered by service providers brought into the evidence-based equation the presenting needs and preferences of the client.

Figure 7: A Framework for Treatment Delivery: Evidence Based Treatment in Practice
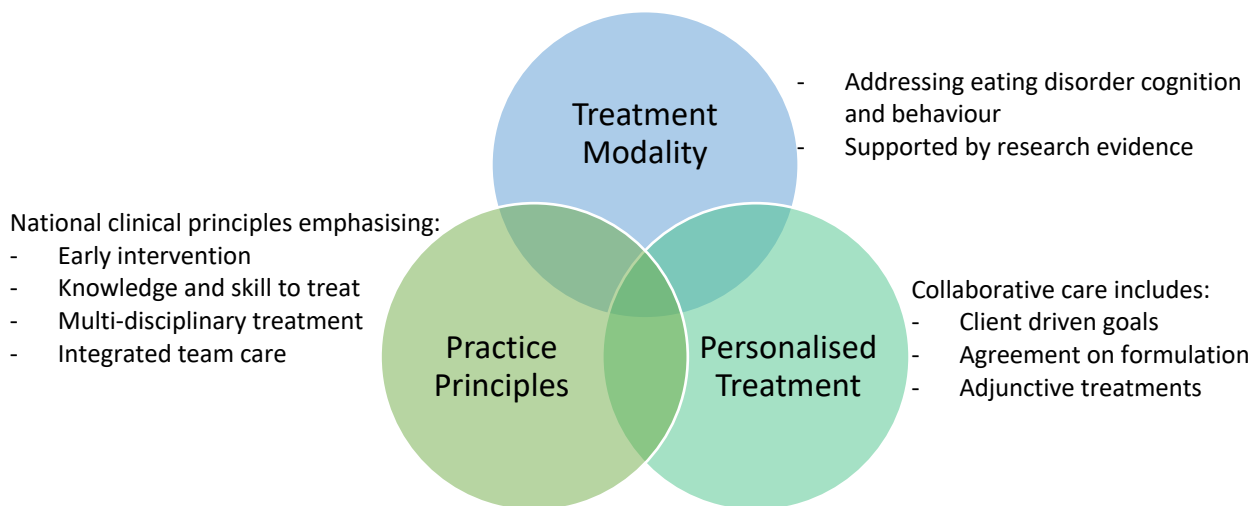
The Trial supported consistent use of evidence-based treatments by providing training and requiring the use of validated assessment tools (EDE-Q and ED15) together with data monitoring and tailoring support to address emerging needs.

Selecting a Treatment

In the real world, the treatment options offered to clients with eating disorders largely depend on the judgment and training of the clinicians and Trial data indicates a wide variation in clinical practices.

A sample of 159 case conference reports that included relevant clinical data, showed that 49% were likely to be receiving a single evidence-based treatment modality. This included the use of SSCM,

CBT-E, FBT, or GSH with motivational interviewing and RAVES dietetic care as accepted adjuncts to standard treatment approaches. A smaller number of service providers included a mixture of treatment modalities in their initial treatment plans including alternative evidence-based treatments and adjunctive treatments. Preferred treatments included IPT, DBT, ACT and Narrative therapy. Both IPT and DBT are recognised by MBS as evidence-based treatments. There is evidence supporting the use of ACT as an early intervention treatment for disordered eating (Berman, Boutelle and Crow, 2009; Juarascio, Forman and Herbert, 2010; Manlick, Cochran and Koon, 2013) making it suitable for an early intervention population.

Service providers in the Trial achieved treatment outcomes consistent with research benchmarks using a variety of therapeutic approaches, and sometimes blended techniques. The approaches to blending treatment were highly individual. Most frequently CBT-E was combined with a second eating disorder treatment and an adjunctive treatment e.g.
- CBT-E, with SSCM, DBT, Mindfulness, Chain Analysis and MI
- Individual SSCM with CBT group therapy
- CBT-E with ACT and schema work
- CBT with Focal Psychodynamic Therapy

Previous studies have shown that the usual approach to psychological treatment in private practice is 'eclectic' and 'integrative' (Turner, Tatham, Lant et al., 2014; Von Ranson, Wallace and Stevenson 2013; Waller, 2016). Service providers select elements from different treatment modalities to create an approach that best suits their own therapeutic style and the needs of their clients.

Manualised treatment is a very helpful playbook for ED treatment.
(Feedback from Trial Training Session)

Reluctance to use manualised treatment approaches has been associated with service provider self-efficacy (Brown and Nicholson, 2018) their beliefs about the primacy of the therapeutic relationship (Mulkens, de Vos, Graf et al., 2018) and anxiety about distressing the client (Turner et al., 2014).

I think that some clinicians don't want to confront the eating disorder. They forget the importance of keeping people safe within clear boundaries and non-negotiables. By focusing on being kind and understanding they risk colluding with the eating disorder. (Trial Stakeholder)

The dominant issue for service providers in the Trial seems to have been one of a perceived lack of fit between manualised approaches and usual practice. The issue of 'fit' with existing practice has been identified in other studies as a barrier to implementing change in health care (Weaver, 2010; Miles and Mezzich, 2011; Dunsford and Reimer, 2017). Evidence suggests that clinicians do not change their practice to deliver manualised eating disorders treatments where they believe that these treatments are inconsistent with their own theoretical orientation (Cooper, Bailey-Straebler, 2015). The clinician is likely to preference their clinical experience and their personal 'comfort zone' over other factors in decision making (Peterson, Becker, Treasure et al., 2016).

Results of comparative studies suggest that any of the existing evidence-based psychotherapies for anorexia nervosa can be equally effective (Grenon, Carlucci, Brugnera et al., 2019) whilst there is

clearer evidence supporting CBT and CBT-E for non-underweight bulimic eating disorders (Fairburn et al., 2015; Poulsen, Daniel, Mathiesen et al., 2014). As new treatments continue to emerge for eating disorders, the emphasis should possibly be on adherence to key eating disorder treatment practices rather than on fidelity to a specific treatment modality, moving to a personalised medicine approach.

4.4 Treatment Integrity

Fidelity to treatment protocols was expected to increase the likelihood of achieving similar treatment outcomes to research trials. Client data was reviewed for five key aspects of practice to determine the extent to which individual therapy sessions were provided in line with evidence-based treatment modalities:

- Regular weighing.
- A structured approach, with specified goals and agendas set for each treatment session.
- Discussion of food, weight, and body image issues at every session.
- Regular assessment of eating disorder thoughts and behaviours (ED15 questionnaire).
- Family involvement especially for clients under 18 years.

The Practice of Regular Weighing

Beliefs about weight and body shape are part of the core psychopathology of eating disorders. Most evidence-based treatments for eating disorders include weighing as a key practice. Attitudes towards weighing clients have changed as treatments for eating disorders have been refined over the past thirty years. Open-weighing is now integral to CBT-E (Waller and Mountford, 2015).

A low rate of fidelity to key practices such as weighing (Cowdrey and Waller, 2015) has been noted across clinical providers. Weighing is a cause of stress for some clients and their service providers and studies show a high level of variation in when and how service providers weigh clients with eating disorders (Waller and Mountford, 2015). Feedback from the Trial's training workshop evaluation highlighted the challenges of manualised treatment for some service providers e.g. *"professional clinician as a weigher – this is a challenging concept"*.

Some service providers nominated one member of the treatment team to weigh rather than repeating this practice at all sessions e.g. *I don't weigh my clients. I know I am supposed to but the focus of therapy isn't on weight. Knowing that the dietitian and the GP are regularly weighing and having access to their notes helps me to raise this subject when needed. (Mental Health Service Provider)*

In a sample of 46 mental health and dietetic service providers registered with the Trial, 20% weighed clients regularly, 37% weighed at between half and three quarters of sessions, and 43% weighed at less than half of all sessions. Only 3 service providers recorded weights at every treatment session; 6 service providers never recorded a client weight.

Weighing regularly, at half or more of all sessions emerged as a significant moderator of treatment outcomes. Regular weighing results in a significant decrease over time in two key indicators of an eating disorder, weight concern and body preoccupation and dissatisfaction. The practice of regular weighing did not increase the rate of dropout from treatment, suggesting that it was well tolerated by clients. As regular weighing is an important practice in the treatment of eating disorders, further work is required to identify strategies to overcome barriers to this practice, for both service providers and clients.

Measuring Progress in Treatment

International guidelines promote the use of outcome measures for eating disorder cognition and behaviour and for physical and mental health comorbidities, as an essential factor in shared care (NICE, 2019). The Trial required service providers to measure progress using a validated measure, the ED15. The use of validated assessment tools as measures of progress in treatment sessions did not seem to be a part of existing routine practice. Time was required to introduce this concept to a point at which data was routinely submitted.

The Trial has brought a different structure to the way we work, and we want to keep practices like using the EDQ and ED15 questionnaires. Monitoring progress has been useful for us and for the clients.

We have changed our approach to treatment because of the Trial by putting a clear limit on the number of sessions we provide. This plus using the ED15, has helped us focus on progress. An unexpected outcome has been a reduction in waiting times for treatment. (Service Provider)

I have found how important it is to establish non-negotiables with the client early in treatment. The client needs to understand the process that they have to work through. They need a global sense of 'this is where we are headed'. (Service Provider)

Using the ED-15 at each session has been an imposition but it has its uses. It means that we talk more about eating that I would usually, but it has been helpful to make sure that we touch on food and weight. It helps in working with the dietitian. (Service Provider)

The Trial was successful in supporting service providers to integrate some key eating disorder treatment practices, notably the use of measurement tools such as ED-15, with limited success in encouraging regular weighing.

Treating the Eating Disorder

All evidence-based therapies work towards eating and weight normalisation early in treatment (Hay et al., 2014). Feedback from some service providers indicates that talking about weight and eating is not a priority theme in treatment sessions. To be an eating disorders treatment the approach must specifically address eating disorder cognition and behaviours. The following checklist summarises key features of eating disorders treatment that may be helpful to GPs and service providers in identifying which aspects of eating disorders treatment are a priority for inclusion in practice.

Working with the client towards a shared understanding of the illness and recovery process is an important first step in evidence-based treatment (Heruc et al., 2020). Early psychoeducation and transparent approaches to treatment planning can improve the client's belief that the treatment proposed will be effective. When the clinician and the client have different expectations, the rate of premature withdrawal increases (Seidinger-Leibovitz, Malta, Rodrigues et al., 2020).

A lack of family support was a complexity noted for young people in the Trial resulting in the absence of family from treatment sessions. Several young people in the Trial were separated from their families. Where safe and appropriate, the service provider and care navigator repeatedly reached out to the family to engage them, however, this did not often meet with success.

Approximately 10 clients from the whole group participating in the Trial (215) subsequently attended an eating disorder treatment service delivered by Queensland Health (SCEDS or CYMHS). These clients had nominally received CBT-E or FBT, however they were not able to describe key practices inherent to these treatment modalities. Lack of clarity about treatment at any stage in stepped care makes it harder for the person to engage in further step-up or step-down treatment. The client and their family should understand the treatment options, and what a program of treatment will involve. The goals of treatment and possible consequences should be discussed, and informed consent should be recorded.

Selecting Treatment Practices when Clients have Complex Needs

The goal of treatment is sustainable remission to reduce the risk of chronicity and health consequences. Recovering from an eating disorder involves a challenging level of change in lifestyle, diet and thinking. The application of this basic practice guide should be interpreted in the context of client perspectives. While it is essential to directly address eating disorder concerns it is also

important to enable the client to build strengths for sustainable recovery. From a lived experience perspective, the most important issues are developing a strong sense of self as someone who is capable, confident and has a sense of control (Vanderlinden, Buis, Pieters and Probst, 2007; Butterfly, 2016).

People receiving treatment often report a sense of disconnection between their own goals and those of their service provider which has an impact on their motivation for recovery (Butterfly, 2016). Studies suggest that clients are more likely to drop out of treatment if they feel it focuses too much on food and body image rather than dealing with emotional issues (Vinchenzo et al., 2021).

An eating disorder makes other aspects of the person less visible. If you focus on eating in treatment, you do the same thing. Therapy needs to focus on the important issues and eating isn't always one of them. People lose a sense of their self, their identity with an eating disorder. The eating disorder fills the gap. They need to develop a sense that they matter. They need to renourish but with a sense of agency that they can control what is happening. (Service Provider)

The challenge for the service provider is finding the balance between addressing eating and weight related thoughts and behaviours and strategies that help to build the clients confidence and capacity to do the work of recovery. Getting the balance right is a process of continuous adjustment; a partnership between the client and their treatment team in which monitoring progress and motivation play a key role. Client feedback and psychometrics are both critical to maintain the balance between treating the eating disorder and supporting the person to do the work of recovery.

There isn't a treatment that is right for everyone. We need to be more flexible in how we approach treatment but without losing the non-negotiables and the awareness of progress which are essential to keep people safe. (Service Provider)

Keeping both the ED and how it is presenting and the preferred identity of the person as a focus in each session is important. (Focus Group Participant)

Often the eating disorder is blamed for every single decision the person can make. The person can be left feeling like people only see them as an eating disorder not the person they are deep inside and that everything else is forgotten about. I feel it is important to involve the person in their treatment and bring in a balance… so they are seen as a person experiencing an eating disorder rather than a person who is anorexic. (Focus Group Participant)

The collaborative approach is consistent with the good practice principle of providing personalised approaches based on regular evaluation of client progress (Heruc et al., 2020). Formulation, working collaboratively with the client and other treatment providers to identify which factors in a client's life are maintaining the others and which are most likely to be malleable at the present time, is an essential part of treatment planning for eating disorders (Tarrier and Johnson, 2015; Troscianko and Leon, 2020).

> The core of recovery-oriented practice for people with eating disorders may be summarised as:
>
> **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
>
> (Insights in Recovery; Butterfly, 2016)

Complexity as a Factor in Treatment Access

The people most likely to seek help also present with the most severe and diverse range of complexity factors. Treatment approaches and health care systems that do not reflect this complexity create additional barriers to treatment access.

The way we compartmentalise health, treating different issues as if they are separate from each other, is a systemic problem. Eating disorders and other issues all come together in individual lives and we have to work with the person where they are in life. (Service Provider)

In the real world we don't see the pure conditions that are written up in the textbooks and research. We see people who have multiple issues to deal with. We need more real-world trials in which no-one is excluded from treatment. (Service Provider)

90.5% of Trial clients had at least one comorbid mental health condition, with many having severe multiple physical and mental health challenges.

The clients who come here have really complex lives. They have the psychological and physical health issues of an eating disorder, but they also often have trauma and suicidality in the background. They are juggling illness and life responsibilities with family relationship issues and limited finances. I don't think that the MBS items reflect the real world of complexity and the interaction of different life issues. It is this complexity that makes someone need help, not just the severity of the eating disorder. (Service Provider)

Complexity is often defined solely in terms of the eating disorder. The eating disorder develops and becomes entrenched in the context of the complexities of the person's life. These complexities perpetuate the eating disorder and vice versa, the eating disorder exacerbates comorbid mental health conditions, physical health conditions, stress, low income, and relationship difficulties. Treatment outcomes could be improved if eligibility criteria for eating disorder services included the complex social and economic circumstances of many people with eating disorders (Webster, Rice, Bhattacharyya et al., 2019).

4.5 Integrated Team Care

Multi-disciplinary treatment is an essential principle of evidence-based practice for eating disorders, delivered with interprofessional collaboration between the different service providers on the treatment team:

- *NEDC National Standards Schema for eating disorders (2012)*:
  Safe Treatment: all clients must be treated for the physical, psychological, nutritional, and functional aspects of their eating disorder. Best practice eating disorders management requires an integrated, multidisciplinary network of primary and specialist care. Eating disorders treatment should be delivered by trained and experienced practitioners.

- *ANZAED Eating Disorder Treatment Principles (2020)*
  Multidisciplinary care team (MDT). Treatment of eating disorders should be multidisciplinary, including a medical practitioner, mental health professional and a dietitian if accessible. Respective roles across the MDT should be clearly documented and understood, and a designated clinical lead identified.

Clients were not directly asked about their experience of integrated team care, however several clients volunteered comments emphasising their increased confidence in treatment e.g.

The fact that I knew the psychologist, dietitian and GP were reviewing my case and discussing my case together regularly, has also given me confidence. I felt the further into treatment we went the more they were working as a team and by the latter sessions there was such a cohesiveness in the messages provided to me, I felt able to apply and progress forward. (Care Navigation Files)

Service provider feedback on the pros and cons of working in an integrated team include improved experience for clients, pooling knowledge and resources, consistent treatment plans, and feeling more supported. The main challenge identified was the increased workload involved in participating in team meetings.

Table 10: Pros and Cons of Integrated Team Care from a Service Provider Perspective

Benefits of Integrated Team Care	Challenges of Integrated Team Care
- *Much better outcome for the client if all care providers are on the same page, giving the same unified message.* - *I have only experienced advantages since working within a shared care team. Advantages include client's confidence in the support and treatment they are being provided, execution of treatment as it is reinforced by multiple team members, information and formulation sharing to ensure treatment is appropriate.* - *Great to experience the differing foci of professionals of different training- pooling resources and approaches for the combined benefit to the client.* - *Better all-round care, discussion of cases.* - *It is incredibly helpful to all be aligned working on the same goals and have that wrap around support for the client.* - *Consistent plan and treatment for the client, feeling more supported, better risk management*	- *The biggest challenge is the time-consuming nature of the work* - *Sometimes difficult to schedule time in crowded schedule* - *Coordination of a meeting and unpaid time involved in meetings, letters.* - *Some professionals don't really "share" the care. Lack of collaboration.*

Clarifying Team Roles

Some service providers report confusion and lack of clarity about their roles in assessment and treatment planning, with uncertainty around the practical working relationship between the GP and the allied health professional in completing assessments and making the diagnosis.

It helps to be really clear about who does what role in the treatment team. There are tasks in CBT-E that can best be done by the dietitian leaving more time for the psychologist to focus on therapy.
(Service Provider)

The Role of GPs

Service Provider Interviews with allied health providers identified a lack of GP involvement as a challenge in integrated team care.

Medical monitoring is not being done as frequently as it should be for patient safety. There is a need to educate GPs on eating disorders as chronic conditions. Eating disorders in adults with symptoms presenting for three or more years should be treated as chronic conditions, regardless of severity, in the same way that conditions such as diabetes and asthma are treated with a preventive focus.
(Service Provider)

The usual model of practice for GPs is to treat or to refer on to a specialist for treatment. All GPs have a role in identifying and referring clients with an eating disorder. When eating disorders are treated in community settings, GPs are also expected take responsibility for medical monitoring and care coordination (Marks et al., 2003). The Trial presumed that the GP would coordinate team care. In practice, the role of coordination often fell to the allied health providers with the GP role primarily focusing on referral and medical monitoring. GPs also report that they do not have the time to complete both the medical and mental health assessment requirements.

The Role of Dietitians

Disordered eating and malnutrition are common in all eating disorder presentations and food is therefore an important issue in treatment approaches. Dietitians need to be involved in treatment to ensure that the client receives best practice nutritional counselling and management (Jeffrey and Heruc, 2020; McMaster, Wade, Franklin and Hart, 2021).

The Trial introduced dietitians as a recommended part of the eating disorders treatment team: 82.8% of clients (N=130) received at least one session of dietetic care and 27 clients (17.2%) chose not to receive dietetic care. Usage of dietetic services ranged from zero to 15 sessions. Of those who accessed dietetics at least once, the mean number of sessions was 6.7 (*SD* 3.2) This may provide a useful benchmark for planning the frequency of dietetic sessions.

The number of sessions of dietetic care did not have an impact on rate of improvement. However, those who received three or more sessions with a dietician were less likely to drop out of treatment. Client feedback ranged from concerns about the affordability of sessions with a dietitian to strong endorsement of the value of seeing both a mental health professional and a dietitian e.g.:

I found it rewarding having both a psychologist and dietitian in my team. (Care Navigation Case Files)

Having the psychologist and dietitian provide the treatment they did, has meant that food no longer serves non nourishing purposes for me. Food has become very good now. My body image has significantly changed, I'm amazed now the way my eyes and brain perceive my body. For the first time in my life I like my body. (Care Navigation Case Files)

Going once a week has been helpful. It feels like a genuine check-up. It is not too often but close enough to feel like I am being supported. The homework tasks have been helpful and it has been useful to see both the psychologist and the dietitian. (Care Navigation Case Files)

Clarity around the role of the dietitian in the treatment team is essential for the client as well as other members of the treatment team (McMaster et al., 2020).

The role statement for dietitians providing treatment for eating disorders in community care (Dietitians Association of Australia, 2013) describes a dual role with two groups of functions: (1) working directly with the client to provide assessment, education, and counselling and (2) working with the multi-disciplinary care team to contribute to care planning and review and acting as a nutrition resource for other team members and the family. The number of sessions of direct care provided by dietitians may be modified for some clients by the provision of nutritional advice to the treatment team or family. To undertake this role, the dietitian requires an understanding of the evidence-based psychological treatment modalities.

In the Trial, treatment teams formed and defined roles to accommodate the levels of skill and knowledge of the individual service providers as well as to meet the needs of the client. This flexibility is important for 'virtual treatment teams' and its success is demonstrated by positive client feedback and treatment outcomes.
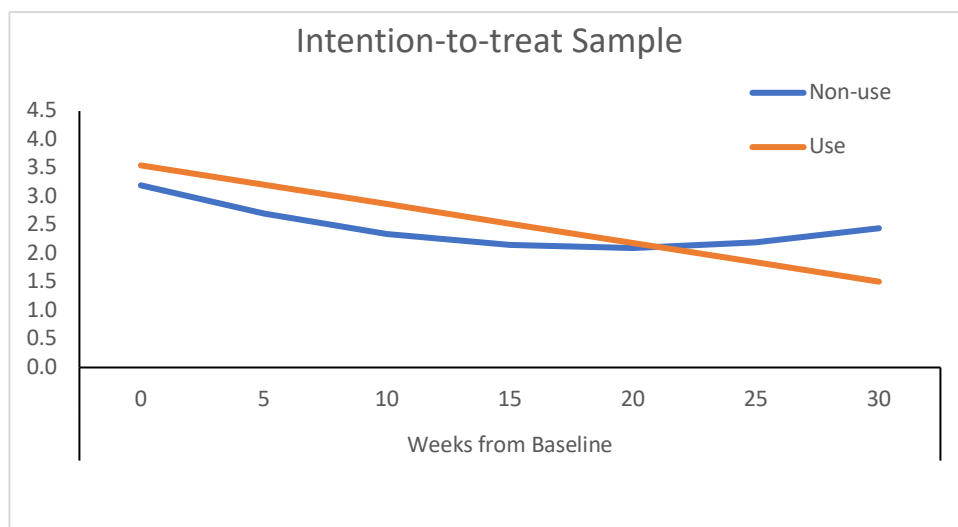
Case Conferencing

Integrated team care means more than having multiple service providers working with a client. The purpose of integration is to ensure a consistent approach to meeting client needs and this requires a high level of communication between the service providers, which can be challenging when each service provider is working independently in the community.

Case conferencing, where all service providers engaged with an individual client meet regularly to monitor progress and discuss next steps in treatment, was recommended by the Trial. This was supported by payment of a rebate to each participating service provider for up to 6 case conference meetings; this number was selected to enable monthly meetings over a six-month course of treatment. Use of these sessions was at the discretion of the treatment team.

Regular case conferencing (2 or more conferences over a six-month course of treatment) appears to have a protective effect, ensuring an ongoing decrease in eating disorder cognitions rather than the rebound effect seen here in those without regular team meetings. Those whose treatment team had two or more case conferences were also more likely to complete treatment.

Graph 4: Case Conferencing as Moderator of Change in ED Cognitions

Intention-to-treat Sample

Services providers welcomed case conferencing while noting the difficulties in finding time for this addition to treatment.

Case consultation has been really helpful. It prompts more frequent review of what is happening in treatment, and it has enabled us to work more closely with GPs. We have needed the Care Navigator to remind us to schedule meetings as this hasn't previously been our usual practice. (Service Provider)

Case conferencing just makes a huge difference. Integrated team care is the best way to treat eating disorders and case conferencing makes this a reality. (Service Provider)

It is impossible to get three people together for a case conference. When we do this it is often out of hours, after work or on Saturday morning. It is harder when you don't have an established relationship with the other clinicians. We try but we always seem to end up with less than the recommended number of case consults. (Service Provider)

Integrated team care provides a safe approach to treatment for eating disorders that benefits service providers as well as clients. Working together to share the burden of care can improve treatment outcomes and reduce the time commitment and stress of each individual clinician. Linking service providers in a shared care approach is one of the essential strategies to improve access to treatment and outcomes (Johns et al., 2019).

Chapter 5: Navigating the System

For a client to get access to eating disorders treatment, they need to be identified and diagnosed, find a clinician who treats eating disorders and who provides affordable care in an accessible location.

In practice there needs to be a network of knowledgeable service providers who can identify the person at risk and take the necessary action to connect them with an appropriate treatment team.

The Trial investigated screening for early identification and referral as a strategy to support access. This project was successful in engaging service providers and in identifying people with or at risk of eating disorders early in the development of symptoms (within first 3 years).

An eating disorders treatment team were co-located with Headspace to improve access for young people and this approach has also shown promise as a way of removing the barriers of cost and physical access and integrating eating disorders treatment with support for other mental health issues.

The most significant factor in care navigation was the appointment of a local eating disorders Care Navigator who was able to negotiate rapid access to affordable treatment.

This chapter describes the screening project, the approach to early intervention through partnership with Headspace and the care navigation role.

5.1 Prioritising Early Intervention

The first principle for good eating disorders practice is early intervention (Heruc et al., 2020; NEDC, 2018). Interrupting the cycle of illness early is important. Reducing the time between the onset of eating disorder symptoms and the start of evidence-based treatment reduces the risk of eating disorder behaviours becoming habitual and contributes to a reduction in risk of physical health consequences (Potterton, Austin, Flynn et al., 2021). This is the best evidence-based approach to reducing the impact of illness in individual lives and reducing the high costs of healthcare associated with eating disorders.

Knowing when to Intervene

Defining the start of an eating disorder and the best point for intervention presents challenges (Lang et al., 2016). Most studies have defined early intervention in terms of time, with a focus on the first three years from symptom development (Lang, Glennon, Mountford et al., 2016). However, early symptoms often start well before they meet the criteria for a full or partial syndrome eating disorder. Levels of clinical significance for eating disorders are not defined in the DSM-5 (Mitchison, Mond, Bussey et al., 2020) and the Trial did not impose a definition of clinical significance and no lower limit was established for early intervention.

In the absence of clear indicators for early intervention, the Trial identified early intervention as meeting the DSM-5 criteria for an eating disorder with motivation to participate in treatment and one of the following:

- Duration of illness less than 3 years.
- No prior treatment for an eating disorder.
- Support for sustained remission after specialised eating disorder treatment.

People with lower levels of eating disorder severity usually have the best treatment outcomes (Vall and Wade, 2015). The Trial found that clients with a lower severity at the start of treatment, measured by ED15 scores, were more likely to complete treatment than those with higher (clinical) levels of severity. Yet people with eating disorders are most likely to seek help when they have severe symptoms. It is vital that we develop understanding of how to get treatment to people with or at risk of eating disorders as early as possible.

GPs in the Trial raised concerns about referring to an eating disorder service 'too early' when those services were perceived as being specifically for the most severely unwell. Service providers raised questions about clinical significance and the best time to start treatment. These questions were considered by a focus group of 45 service providers and key stakeholders in August 2021. There was strong consensus support for early intervention, with an emphasis on providing treatment when the opportunity arose (i.e. when the client was seeking help for the eating disorder or a related condition) rather than waiting for a specified level of clinical severity or medical consequence. The emphasis was on preventing the eating disorder from becoming severe or chronic.

In this context, participants noted the importance of screening and access to early intervention treatment as people with lower levels of clinical severity were less likely to seek help, believing that the problem was something they should be able to deal with by themselves.

As a clinical psychologist I can testify that when clients have a short history of ED (6 months to a year) it is so much easier and faster to treat. This in turn reduces heartache for the family, stigma and financial strain. (Focus Group Participant)

The Trial confirms the need to develop service models that support rather than restrict early help-seeking. Models of early intervention are needed that reflect the range of complexity of presentation and the diversity of clinical significance in the early stages of developing an eating disorder.

The Trial has prioritised three early intervention strategies:

- Promoting screening by GPs and other community health service providers including dietitians and school nurses.
- Enabling access to two assessment sessions, separate from a planned course of treatment, to encourage referral and early investigation of symptoms.
- Providing rebates to reduce the cost of early intervention treatment without restricting access based on the level of severity of illness.

Together, these strategies have enabled identification of people who have not previously had access to eating disorders treatment. They have not been as successful at identifying people early in the development of illness.

5.2 Identifying Clients with Eating Disorders

For early intervention to be a reality, there needs to be a network of knowledgeable service providers who can identify the person at risk and take the necessary action to connect them with an appropriate treatment team. Without initial identification and diagnosis, the client cannot progress towards treatment. This is one of the main reasons for delayed access to treatment. Identification is less likely to happen if the GP does not ask questions about eating disorder symptoms (Fursland and Watson, 2014) or questions about mental health (Hay, Ghabrial, Mannan et al., 2020).

People in the early stages of developing an eating disorder rarely volunteer information to health professionals on their eating behaviours making early identification challenging. Opportunistic screening in general practice for high-risk groups is the best available approach (NEDC, 2017). While the use of validated screening tools in GP practice is recommended, adoption in individual GP practices has been slow.

The Trial Screening Project

Between July 2020 and May 2021, the Trial provided information and outreach to GPs, school nurses and dietitians in the Sunshine Coast region to promote screening practices. The emphasis was on recognition of disordered eating as an indicator of risk for eating disorders and on the medical consequences for several high-risk groups of clients including people with weight related health issues, diabetes, infertility, and depression. Disordered eating is a persistent disturbed and unhealthy eating pattern not explained by medical needs.

GPs are more likely to identify an eating disorder if there are clear referral pathways available (Banas, Redfern, Wanjiku et al., 2013). As an incentive to participate, the Trial provided access to two assessment sessions for any client whose responses to screening questions suggest disordered eating may be present, and access to low-cost treatment through the Trial for eligible clients. A dietetic care pathway of three sessions was introduced for people identified as having disordered eating who did not meet the diagnostic criteria for an eating disorder.

The information provided to service providers promoted the use of the *Screen for Disordered Eating* tool. This validated tool for detecting eating disorders in primary care is inclusive of binge eating disorder (Maguen, Hebenstreit, Li, Dinh, 2018). In the Trial, a preliminary question was added to enable the GP to initiate the conversation with the client:

Are you satisfied with your eating patterns?

While the screening project reached out to many primary health practices, there was a goal to recruit a smaller cohort of practices to commit to routine screening of all high-risk clients for the period to May 2021, when Trial referral intake ceased. Of the 44 GP practices approached, 42 practices, involving 73 GPs, took up the opportunity to routinely screen for eating disorders. In addition, 19 other health professionals in positions suited to first identification of an eating disorder (dietitians, mental health social workers and school nurses) adopted screening practices. These

numbers do not include those who may be using screening who have not provided information to the Trial. This high rate of involvement has been achieved through a strategy of personal contact and flexibility to help each practice adapt screening to suit their usual approaches.

Ninety (90) referrals were received through initial screening by GPs. 81% of these screening referrals were identified as requiring treatment. Fifty-five (61.1%) went on to a full course of treatment with the Trial (20 sessions) and a further 18 went on to eating disorder treatment outside the Trial (e.g. MBS eating disorders plan). Seven (7.77%) were identified as having disordered eating and received a brief intervention dietetic care. Only 10 (11.11%) were found not to have an eating disorder at this time.

Table 11: Profile of Early Intervention Referrals

Data Field	Categories	Trial Participants
Duration of illness N = 90	*Early Intervention* 0 – 12 months. 1-3 years	31 (34.44%) 11 (12.22%) 42 Early Intervention (46.66%)
	Later Intervention 3 – 10 years 10 years or longer No useable data	14 (15.55%) 23 (25.55%) 11 (12.22%)
EDE-Q Global Scores N = 65	Equal to or greater than 3 2.0 to 2.96 Less than 2.0	40 (61.53%) 12 (18.46%) 13 (20.01%)
Age N = 90	14 – 17 years 18 – 29 years 30 to 50 years Over 50 years Not eligible (under 14 years)	37 (41.1%) 27 (30.0%) 13 (14.44%) 11 (12.2%) 2 (2.22%)
Previous Treatment N = 90	No previous treatment Previous ED treatment Not determined	75 (83.33%) 11 (12.22%) 4 (4.44%)

Note: Information included in referrals and early assessment records was variable therefore sample sizes vary.

Screening identified led to 40 people in the first three years since onset of symptoms of an eating disorder (61.53% of sample) and 75 (83.33%) people who had never received treatment for an eating disorder before. This compares with 64.6% of clients, from a sample of 217 closed and active cases across the whole Trial, who had not previously received treatment for an eating disorder. This suggests that the Trial was successfully engaging the target early intervention population and that rates of identification improved with the introduction of screening.

More than half of referrals received through the screening project (68.8%) were identified using the SDE tool either alone or followed by the EDE-Q assessment tool. Other referrals came from clinicians who preferred the SCOFF tool (10%) or who preferred to use their own approach (14.4%).

The screening tool [SDE] was easy to use and provided good structure in a concise way to assess and easily identify disordered eating. (Headspace)

Screen for Disordered Eating: Primary Care Screening Questions

1. Do you worry that you have lost control over how much you eat?
2. Do you often feel the desire to eat when you are emotionally upset or stressed?
3. Do you make yourself sick when you feel uncomfortably full or to control your weight?
4. Are you often preoccupied with a desire to be thinner?
5. Do you ever eat in secret?
6. Have you or any member of your family suffered from an eating disorder?

A 'yes' response to any question indicates further investigation for disordered eating.   (Maguen et al., 2018)


An additional training session on identifying and supporting people with an eating disorder was provided for interested GPs in June 2021. This session was attended by 29 GPs and 11 other health professionals. Feedback highlighted the importance of information on how to manage the limited time available in a standard appointment, developing understanding of assessment tools and having a clear understanding of local referral pathways.

Screening does not happen in isolation. It is one step in a sequence of from initial clinical observation, initiating inquiry into mental health and eating behaviours, to referral when indicated. Identification of an eating disorder has little purpose unless there are treatment options readily available (Waller, Micali and James, 2014).

The trial provided support for each stage in the screening sequence:

- GP training and information to support clinical observation.
- Simple introductory question to initiate the conversation.
- Screening tools available on desktop.
- Easy referral process.
- Triage and assessment pathway as well as treatment pathway.

Figure 8: Supporting the Process of Early Identification
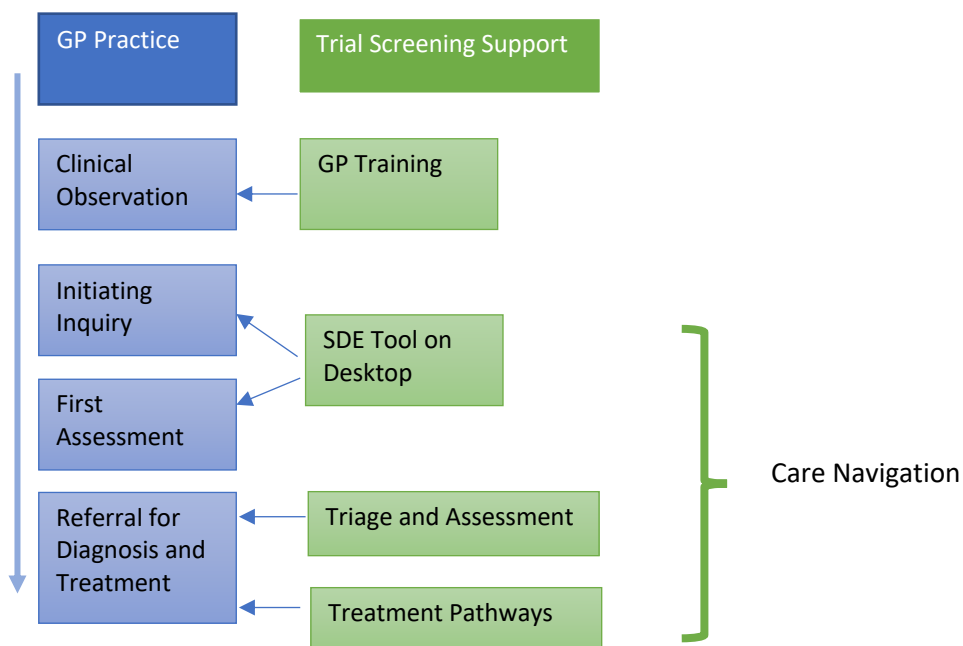
The Trial's provision of a treatment pathway, with support through care navigation to access alternative treatment pathways when needed played a critical role in engaging GPs and others in screening. The use of a triage and assessment pathway as an intermediary step before referral for treatment, assisted GPs to feel more confident in identifying possible eating disorders.

I realize that eating disorders are lot more complex than most GPs are aware of. The Trial made me more aware of sub-clinical because there was a pathway we could use. When there is nowhere to go there is no point in referring. We need to start earlier with awareness of nutrition and wellbeing, rather than waiting until someone meets the diagnostic criteria for an eating disorder. (GP)

The Trial has been helpful. It is really useful to have a basic referral template that only takes 5 minutes to complete. Having access to a care navigator who can triage referrals and be the problem solver and connector is the most useful part of the Trial. (GP)

5.3 Identifying Referral Options

Most people rely on their GP to know, or at least to have ready access to information about where to refer them for eating disorders treatment. When integrated team care is needed, the GP must be able to identify two or more service providers who have:

- The training, knowledge, and skill to treat eating disorders.
- Ability to work in an integrated shared care approach with other professionals, with – established connections with other potential team members.
- Experience in treating trauma or specific comorbid conditions.
- Offices in an accessible area.
- Current capacity to accept new clients, preferably with no waiting list.

Finding a clinician requires more than a list of credentialled treatment providers; it requires a network of informed, skilled, and interconnected service providers. The GP needs to have practical knowledge about who is available now and which treatment approach may be compatible with the client's needs. For GPs who see small numbers of eating disorders in their practice, maintaining up to date information of this sort is unrealistic.

The Trial provided a local source of this information. National information services play an important role however, the Trial has demonstrated the importance of local knowledge. Relationships with local service providers enable reduction in waiting times, negotiating of reduced fees and formation of treatment teams to meet each client's needs. The lack of a local presence for care coordination in the Gympie area was also identified as a potential problem that may have contributed to lower rates of treatment completion for clients from this area.

Embedding Eating Disorders Treatment in Headspace

One of the challenges identified for clients aged 14 -25 years was the need for access to low or no cost services that were easy to reach, often by public transport, and could provide both mental health and dietetic care in one location. The community model used by the Trial, with individual service providers in different locations, was found to be too expensive and too difficult to access for many young clients. The location, model and team approach of Maroochydore Headspace offered an opportunity to develop a 'one-stop shop' to address these issues.

The Trial negotiated a partnership with Headspace to co-locate two teams of eating disorder service providers in the Headspace centre. Each team comprised a psychologist or mental health social worker and a dietitian with capacity to provide eating disorders treatment twice a week. To offset the additional administrative load, the Trial paid a 20% administrative fee to Headspace, in lieu of the fees normally paid by the service providers. The Headspace intake team and other Headspace clinicians were provided with the same information as GPs participating in the screening project and were encouraged to refer for assessment when disordered eating was indicated. The Trial Care Navigator continued to provide triage support and process referrals within the Trial's protocols.

The opportunity for clients to have a dietetic session following psychology session for the most part worked seamlessly and created a cohesiveness, improving connection between clients, their families, and the treating team. Many of our clients have limited resources and need access to public transport so found it easier and simpler to see both clinicians in one location. (Headspace)

The Trial was well structured so we knew referral triage would be attended to consistently and quality treatment interventions employed. (Headspace)

Service provider focus groups identified a gap in services for youth and young adults between the early intervention services of Headspace and the Child and Youth Mental Health Service. As part of the partnership model, links were strengthened with Child Youth Mental Health Service (CYMHS) and where appropriate shared care arrangements and referrals were put in place. Two clients have received treatment for their eating disorder through Headspace whilst receiving care through CYMHS for comorbid conditions.

Sixty-nine referrals relevant to Headspace were received from a mixture of sources including GPs and Headspace clinicians. Fifty-three clients (24% of all referrals) proceeded to receive treatment from the service providers co-located with Headspace. Ten chose to access alternative treatment options (e.g. CYMHS or an MBS plan with a private practitioner) and a further three were found to be medically compromised and were referred for urgent medical review. Four of these referrals did not meet the eligibility criteria for the Trial. Data analysis is based on a sample of 36 clients of the total number of referrals to Headspace for whom complete data was available.

When compared to the whole cohort of Trial clients, referrals to Headspace were less likely to have received previous psychological treatment for an eating disorder. Once receiving treatment, Headspace clients were more likely to have received 3 or more dietetic sessions (OR 7.58; 95% CI 1.72, 33.43) and had a slightly increased rate of case conferencing. Clients receiving treatment through the Headspace initiative were more likely to complete treatment, and this is supported by the identification of case conferencing and dietetic care as moderators of treatment retention.

Being able to go to Headspace was extremely helpful and meant I didn't have to pay a gap. (Care Navigation Files)

The partnership approach with Headspace:
  − Improved early treatment access for young people
  − Supported Headspace service providers to recognise and respond to early presentations of eating disorders.
  − Ensured delivery of evidence-based treatment through a trained team of service providers whose focus was on eating disorders.

 Other investigations (e.g. Radunz et al., 2021) have identified Headspace as an appropriate location for early intervention for eating disorders. The Trial's partnership model has shown promise as a way of removing the barriers to access while maintaining the integrity of the eating disorder treatment. Further work would be required to develop and implement the necessary training and protocols in other regional areas.

5.4 Care Navigation

Although I had ED treatment six years ago this was the first time I had a Care Navigator to support and organize a full team. To have her and GP overlook the care and team was very positive.

Care navigator roles are emerging as an approach to reducing barriers to treatment access that is compatible with the principles of integrated care, linking people to relevant care services and contributing to resolution of barriers to care (Valaitis, Carter, Lam et al., 2017).

The role of the Care Navigator in the Trial was to work with both service providers and clients to:

- Build relationships and networks to support an eating disorder system of care for the region
- Triage referrals and match available service providers to individual needs
- Negotiate barriers to treatment access including identifying low-cost treatment services and alternative treatment pathways
- Maintain contact with service providers and clients to facilitate shared problem solving to understand and resolve issues as they arise
- Act as a local point of contact for eating disorder queries and provide information about treatment access

Service providers identified Care Navigation as the single most important component of Trial activity after the provision of rebates:

It has made a massive difference as the first point of introduction with the client and the care providers.

It has provided a more thorough approach, rather than there being many different service providers splintered off within the community.

I believe it has been particularly beneficial for clients by providing an integrated approach, consistency in care, and drawing the team together.

The care navigator role, pulling things together has been really important. Especially the work done to find the right treatment team – clinicians who can work together and who are right for the client.

There is a need for a single point of contact for eating disorders. If you have to make multiple calls to track down the right information and find a treatment team then it is less likely to happen.

During the most active phase of the Trial, approximately 40 enquiries were received each week in addition to proactive engagement with service providers and follow-up contact with clients initiated by the Care Navigator. The number of enquiries has reduced since the Trial stopped taking new referrals. However, there are still 10 to 15 enquiries per week with a focus on eligibility for MBS items, alternative treatment options and specific enquiries by or on behalf of a current client with the Trial.

A key characteristic of the Care Navigation role has been proactive networking which is a factor in implementation of evidence-based services (Rycroft-Malone, Gradinger et al., 2017, 2019; Wilde, Sonley, Crane et al., 2019) combined with knowledge of community-based care. Local knowledge is essential to build relationships with service providers, rapidly negotiate viable treatment teams and affordable care. Care navigation connects agencies and service providers to ensure a functioning service system.

A key part of the Care Navigator role has been finding treatment pathways for referrals which did not neatly fit into the eligibility criteria of any of the available services (i.e., Trial, Sunshine Coast Hospital and Health Service, or MBS eating disorders treatment plan).

The following case illustrates the complexities for clients who have progressed in treatment but who still require ongoing access to care:

17yr old, hospitalised the previous year for anorexia nervosa now experiencing a recurrence of symptoms with GP assessed medical risk due to weight loss and food restriction. Presented to Emergency Department but discharged when temporarily medically stabilised. Diagnosed with OSFED (atypical anorexia) and no longer eligible for limited places in a hospital eating disorders program or for MBS eating disorders plan. A community care pathway with support from CYMHS was identified as a suitable treatment option to prevent further deterioration in health.
(Care Navigation Case Files)

Making the Connection

The Trial outcomes confirm that the cost of treatment and finding a trained and credentialled treatment provider are two priority issues in determining access to evidence-based treatment for an eating disorder. Strategies such as the introduction of MBS rebates and the proposed national credentialing program are targeting important barriers to treatment access.

An additional systems level barrier to treatment access has emerged during the Trial and that is the need for connecting mechanisms, linking service providers together. Eating disorders do not fit easily into the segmented structure of the health system. The National Agenda for Eating disorders notes that these disorders challenge the conventional ways in which health care is organised (Butterfly, 2017). Connection between the components of health care is essential to create a functioning system. Supporting this interaction is important to achieve sustainable change (Amin, 2008).

In response to the question '*how has the Trial changed the way you provide services*?' service providers focused on improved communication, stronger referral networks and greater awareness of eating disorders.

The main benefit of the Trial has been connection. Having a team to work with – the treatment team but also the Trial team and the wider sense of being part of a practice community. Being part of a group has helped me to see what is valuable and what is not. (Service Provider)

Greater engagement with other members of the care team. I have a much greater network of professionals to recommend to clients, it is more streamlined. (Service Provider)

Better communication with other practitioners and improved understanding of their role and my role in patient care. (Service Provider)

Focus groups for service providers in May 2021 (N=21) identified the main benefits of the Trial as:

- Care navigation
- Paid case consultation
- Training
- Triage and assessment session
- Connection with other service providers

Each of these functions relates to connection. The role of the care navigator enabling connections between service providers and clients, and support for case conferencing sessions that help to connect treatment teams have an obvious role in strengthening connections in the service system. Shared local training also emerged as a strategy that helped service providers to develop their own networks. Behind the scenes, collection of local data played an important role in identifying the type of training needed in the area.

Shared training, getting different professionals into the same training, is vital for teamwork.

You don't know what you are going to get out of training before you go. The motivation to attend local training with the Trial has been about connecting with other practitioners in the area. It is helpful to know who else is in the team and how they are dealing with the challenges of treating eating disorders. All going to the same training has also been helpful to get everyone on the treatment team on the same page. The type of training delivered by the Trial links you to local networks, lifts practice and increases enthusiasm.

The primary health care context is dominated by individual independent practitioners and small group practices, loosely connected through voluntary participation in formal and informal relationship networks. The Trial's role has occupied 'the space between' enabling the timely access to care and integrated teamwork that are important components of effective treatment for eating disorders.

The trouble is there is a space between us. We are all responsible for our own practices but not for that space between. That is where the Trial has been really useful, helping to connect us and coordinate activities – things that wouldn't have happened unless it was someone's job to do it.

5.5 Support for Sustained Recovery

From a lived experience perspective, recovery is the process of developing a life that is not dominated by an eating disorder. Eating disorder thoughts often persist after treatment and people can need help to learn to manage these thoughts (Butterfly 2016).

Rates of relapse in the first 12 months post treatment have been measured in a range from 22% to 51% (Keel, Dorer et al., 2005). The highest risk of relapse is in the first 6 or 7 months after achieving partial remission (Richard, Bauer and Kordy, 2005). People with anorexia nervosa continue to have a significant risk of relapse for one to two years post treatment (Carter, Blackmore et al., 2004). The severity of the relapse contributes to the risk of chronicity and is therefore a significant clinical problem (Khalsa, Portnoff et al., 2017).

This represents a dilemma for service providers. Without ongoing intervention there is a known risk of relapse however, continued intervention can itself become disruptive of self-directed recovery.

Holding on to clients beyond the point of recovery doesn't help them. They need to move on to other types of support in the community rather than staying in treatment. (Service Provider)

People need support after treatment. Eating disorders isolate people and keeping connections is vital but ongoing therapy is not the solution, not for the long-term. Recovery coaches seem to make a difference by keeping people connected. (Service Provider)

We do have concerns about how people are supported in recovery once treatment is complete. We need access to counsellors or peer support services to help people stay on track as well as having the opportunity to provide follow-up therapy sessions when these are needed. (Service Provider)

The Trial did not address the need for support after treatment. Service provider feedback has highlighted the need for support as an adjunct to treatment to enable clients to sustain treatment outcomes. When treatment is time limited additional supports are needed to reduce the risk of a self-perpetuating cycle of illness, treatment, relapse, and readmission to treatment. Peer support services are ideally suited to address this gap in the service system.

Conclusion

Eating disorders are described as complex because the different elements of illness intersect to sustain the illness. It takes time to understand what is happening and to make the profound changes in thinking and behaviour that are needed for sustained recovery. The real goal of treatment is not achieving remission but sustaining that status for the following twelve months. This is needed to break the cycle of illness and repeated need for access to health care.

Eating disorders treatment is hard work. People become tired and frightened by the changes they are experiencing. Somewhere around the middle of a course of treatment people seem to experience slower progress and loss of motivation. Keeping the person engaged at this point is a challenge worth investing in; premature cessation of treatment is a risk factor for the development of a longer course of illness.

Dropout rates from treatment in the community are usually high. The Trial has shown how cost of treatment, waiting lists, and lack of team care clash with the challenge of managing comorbid conditions, low income, and complex lives. People who are motivated to recover may nonetheless make the decision to stop treatment, when it seems impossible to continue to carry the load of hard work and cost associated with eating disorders treatment.

The Trial started as an investigation of the potential impact of rebates on access to evidence based treatment. It has shown that rebates play an essential role in improving access to treatment. However, rebates alone were not found to be sufficient to remove the barriers to treatment access. The third factor that has emerged through the Trial is the need for connection. Local care navigation enabled people to access the right treatment and supported service providers to deliver that treatment within the existing health care system.

People with eating disorders need help to navigate their way through the complexities of illness. To get the right kind of treatment, they need help to navigate the health system. Eating disorders treatment requires steps to be put in place that are not a routine part of primary and allied health care in the community. They need integrated team care that maintains the integrity of the eating disorders treatment to reduce eating behaviour thoughts and behaviours.

Service providers also struggle with the complexity of getting eating disorders treatment right within models of non-specialist practice that do not support an intensive team approach. Most GPs will only see a small number of people with eating disorders in a year, and they are not able to maintain their knowledge of eating disorders and of the local eating disorder service system without external support. Providing an assessment-only pathway, before the need to develop treatment plans was beneficial to GPs who lacked the time or knowledge of how to effectively conduct an eating disorder assessment.

We need to keep something like the Trial as a triage step. The average GP will only see one or two cases a year. We need backup to make sure we are diagnosing and supporting correctly. We need a single point of contact rather than having to track down a treatment team for ourselves. (GP)

Good practice principles (NEDC, 2018; Heruc et al., 2020) formed the basis of the Trial model. The approach prioritised early intervention, training and ongoing professional development, collaborative interdisciplinary care, and care coordination. In practice, two other principles, skilled assessment and personalised treatment approaches including session by session evaluation of progress (Heruc, et al., 2020) emerged as unplanned benefits of the Trial's early intervention and data collection strategies.

The Trial found that these principles can be successfully integrated into the practices of non-specialist eating disorder service providers with benefits for both the client and the service provider. The outcomes of the Trial demonstrate that implementation of these principles together can significantly improve the safety and effectiveness of treatment, and address addressing three important challenges to the delivery of eating disorders treatment:

1. Clinician confidence to diagnose and provide treatment, ensuring a sufficient number of service providers able to deliver evidence-based care.
2. Premature withdrawal (dropout) from treatment, helping to reduce rates of dropout.
3. Rates of symptom remission, achieving good rates of symptom remission when compared with research trials.

Early intervention continues to offer the best approach to reduce the impact of eating disorders in people's lives and in the health care system. The Trial demonstrates the need for and viability of service models that support rather than restrict early help-seeking, offering promising strategies to improve rates of screening, and access to treatment through youth mental health services.

Models of early intervention are needed that reflect the complexity of presentation and the diversity of clinical significance in the early stages of developing an eating disorder. Further initiatives are required to ensure that people on lower-than-average incomes and with complex needs have access to affordable care.

Strategies such as the introduction of MBS rebates and the proposed national credentialing program are targeting important barriers to treatment access. Additional support is required at the local regional level to enable service providers to deliver evidence-based treatment effectively for people with eating disorders.

The Trial both fitted in to the local health system landscape and was sufficiently disruptive to facilitate change. The knowledge and relationships generated by the Trial will continue. It is unlikely, however that the size of the service provider cohort treating eating disorders and the referral pathways will be sustained without further local initiative to maintain the connections.

PHNs are well placed to support the development of connections across primary and allied health and between community-based care and hospital and health services care. Further work in real-world settings is required to continue to define the most cost-effective approaches to improving early intervention for people with eating disorders.

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