
# *PSYCHO-EDUCATIONAL THERAPEUTIC INTERVENTION STRATEGY (PETS) 14.12.2017*

## FINAL OUTCOMES & EVALUATION REPORT 2017

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## EXECUTIVE SUMMARY

Over the course of 2016 and 2017 Therapy Partners were commissioned to deliver a pilot program, developing a whole-system approach in order to support children and young people with eating disorders. This whole-system approach was also to include families, support networks and professionals whilst promoting and protecting the emotional wellbeing of the children and young people in treatment.

***The aim of the pilot was to deliver provision across the following key services:***

1. ***TARGETED SUPPORT FOR INDIVIDUALS*** A solution focused, enhanced Cognitive Behavioural Therapy (CBT-E) (Fairburn 2008) approach to children and young people (CYP) to aid recovery, build resilience and to help CYP live their lives to the full.

2. ***PEER SUPPORT GROUPS*** Facilitated peer support groups for parents and carers of CYP with ED using a psychoeducational approach based on the new Maudsley Method to enable understanding of the key themes of ED, build resilience, and lessen the adverse impact ED has on families.

3. ***AWARENESS TRAINING*** To develop awareness training among school counsellors, teachers and teaching assistants around eating disorders

The findings and results evidenced in this report demonstrate that the support provided by Therapy Partners extended beyond the reach of traditional services. The emphasis of the pilot was on early intervention which is a key driver in achieving positive results.

The PETS programme is in line with the NHS Five Year Forward View which emphasises the need for early intervention and service integration, together with the recommended provision of service to be offered within a 5-mile radius of the young person's home.

Therapy Partners have delivered focused CBT-E sessions for young people at locations convenient to them; including school settings, local venues or in the home environment, thus ensuring that therapy was accessible, as recommended in the new NICE (2014) guidelines.

By providing early intervention and scheduling a therapy appointment within a week of referral, we have seen that the best possible recovery outcomes can be achieved. Providing both local, and timely, appointments was also very well received by the young people and their parents/carers.

The overall strategy for PETS was underpinned by feedback received from all of the people worked with, either individually or in groups, including the people who attended training seminars.

Outcomes for the pilot were positive, with the overwhelming response being that help received at the time of need influenced satisfaction and engagement.

Findings show that the pilot has been a success with patients who accessed therapy, group support and training.

## *PROGRESSION*

During the course of the pilot we elicited feedback from our Peer Support Groups, which were initiated for both the young people in treatment and also for their families. As an organisation, we have strived to offer best practice offering an accessible and listening service that could adapt to the needs of young people.

Working with CCG colleagues enabled the pilot to develop into an evolving and person-centred approach that met the needs of the young people and their families.

Our strategy was underpinned by feedback received from all of the people we worked with, either individually or in groups, including people who attended training. It has been co-productive and collaborative, thereby ensuring that all our work has been informed not only by clinical best practice but by feedback from all stakeholders involved in the pilot. One example of this is that referrals have come in from people over the specific age group that was originally discussed and as a result, with approval from CCG colleagues, the age range was increased to 25 years of age, in line with National guidelines.

Other instances have included the need to focus targeted support for families; not only signposting people but also assisting parents in trying to make sense of the young person's journey which helped them remove some of the barriers to the person's recovery. One example of this is the one-to-one support we have offered to families that have experienced severe trauma and loss, together with financial difficulties: by working alongside local charities and writing to a particular family's landlord we managed to avert the family from being evicted from their home.

This final report on PETS1 will highlight our successes so far, whilst providing outcome measures and the breakdown feedback from both young people and their families. It also includes feedback from professionals who undertook the training.

Regular feedback was fed into the Kent Transformation performance data report via our CCG colleagues. This report builds on data gathered and provides evidence of outcomes and narrative from children and young people, family members, carers and professionals.

The aim of our pilot was to provide a package of care, treatment and support to children, young people and families/carers in line with NICE guidance and evidence-based practice. This includes comprehensive assessment, treatment, and managed discharge, or transition to other services.

## *CHALLENGES*

The challenges faced by young people suffering from eating disorders can, for them, at first look insurmountable. Recovery can be possible with early targeted support interventions for them and their families which we can demonstrate from our data.

In terms of an overview, it can be said that there were challenges in implementing our holistic type of supportive therapy. Initial engagement with young people and their family systems and professional services proved to be difficult. Generally, studies show that patients who are affected by an eating disorder are notoriously difficult to engage with, especially if they don't think they have a problem.

Engagement with schools was also sometimes a challenge, but by adapting our approach using different channels of communication, face-to-face meetings, presentations, social media and other technologies dialogue could be continued and trust built; which enabled engagement to commence.

Upon reflection, not providing children and young people with the resources to recover means that their illness may not be cured and that they go into adulthood with enduring problems' (Statistics, Anorexia & bulimia Care, 2015, 30.07.2017) Some of our young patients were testament to this, coming to us with entrenched disordered eating sometimes lasting 10 or more years. This was, coupled with a wide variety of co-morbid mental health conditions.

## *PETS: BACKGROUND, RATIONALE & EVIDENCE BASE*

The Royal College of Psychiatrists (2012) states that 'Family members, including siblings, should normally be included in the treatment of children and adolescents with eating disorders.'

Interventions may include sharing of information, advice on behavioural management and facilitating communication. Further literature reviews also support the use of family therapy for adults and families affected by eating disorders including anorexia, bulimia and obesity.

The National Service Framework for Children and Adolescents, (Department of Health 2004) central themes states:

"All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood."

Eating disorders have a peak age of onset in mid-adolescence. Thus, many individuals start treatment in child and adolescent services and are handed over to adult services.

Transitions from child/adolescent to adult services or from community to in-patient services are often difficult and disruptive for patients and families owing to time delays between assessment and treatment, duplication of information, disruption in bonds with healthcare professionals, and differences in philosophies of care (Treasure et al, 2005).

The research literature concerning the treatment of child and adolescent eating disorders includes both evidence concerning the efficacy of Systemic Family Therapy (SFT) (e.g. NICE 2004 and more recent studies e.g. Eisler et al 2007; Lock et al 2010) and recent evidence about the key role of service context (House et al 2012) which shows that the most effective way of providing clinically effective and cost effective treatment for young people with an eating disorder is through specialist, easily accessible services that are able to deliver highly skilled evidence-based outpatient treatment with minimal need for inpatient care.

The NICE guidelines on eating disorders also emphasise the importance of the patient and carer experience in building a good therapeutic relationship and improving engagement with treatment goals.

Work with families is a significant component of treatment in CAMHS and other child-focused mental health settings. There is growing evidence for positive outcomes from family interventions. However currently little support is available in a community setting outside statutory services and our intention is to readdress the balance by providing support for families at home or in community settings.

Working with individuals together with their families and/or significant others therapeutically enables the use of individuals' relationships as a resource, and reduces stress and difficulties for all members of the family. Systemic family therapy can sometimes include relational work with individuals, psychoeducational approaches and multiple family groups.

## *EMPIRICAL EVIDENCE FOR EFFECTIVE TREATMENTS FOR CHILD AND ADOLESCENT EATING DISORDERS*

In recent years, considerable progress has been made in developing effective family treatments for adolescent Anorexia Nervosa (Robin et al 1999; Eisler et al 2000, Lock et al 2005; 2010) which show that those treated on a purely outpatient basis with an eating disorder focused family therapy generally do well with 60-75% (and in some studies as high as 85-90%) having reached a weight within the normal range by the end of treatment (typically of 9-12 months duration and comprising between 15-25 sessions) and mostly continue to improve, so that at follow-up 75-90% will have recovered.

The relapse rates for those who have responded well to outpatient family therapy are significantly lower (5-10%) than those following inpatient care (Eisler et al 1997; 2007; Lock et al 2006). These findings are reflected in guidelines by the National Institute for Clinical Excellence (NICE 2004) in the specific recommendations for the treatment of children and adolescents suffering from Anorexia Nervosa

They recommend that most patients should be managed on an outpatient basis by a service that has expertise both in the psychological aspects of the treatment and in assessing the physical risk associated with eating disorders. Family interventions that directly address the eating disorders should be offered to children and adolescents.

Assessment and treatment should be provided at the earliest opportunity particularly in those at risk of severe emaciation.

One of the limitations of the treatment outcome studies is the fact that they do not consider the service context in which the treatment was delivered and that treatment trials have generally been conducted within specialist eating disorders settings.

Two recent studies have addressed this issue. Gowers et al (2007) in a randomized study compared inpatient treatment with specialist outpatient treatment and treatment in generic CAMHS. While no differences were found in terms of treatment outcome the specialist outpatient treatment was the most cost effective (Byford et al 2007).

A recent study (House et al 2012) provided a more naturalistic comparison between specialist and non-specialist care pathways. The study compared areas of London that have specialist outpatient treatment provision for children and adolescents with an eating disorder and areas where treatment is provided through generic CAMHS and evaluated the impact this had on identification of cases, the need for inpatient care, continuity of care, the experience of service use and health economic costs.

There were three main findings. First, in areas where there is direct access to specialist out-patient services, identification of young people who require treatment was 2-3 times higher than in areas with no specialist provisions.

Second, regardless of the initial referral, those treated in specialist out-patient services required inpatient treatment in only 15-20% of cases, whereas those offered treatment in non-specialist services this figure rose to 40%; given that a proportion of those assessed in CAMHS were immediately referred to a specialist service the difference between the two care pathways may in fact be higher.

Third, there was significantly higher continuity of care in specialist outpatient services who managed 80-85% of cases themselves without the need for further referrals, whereas in generic CAMHS as many as 80% of cases seen initially there were eventually referred for treatment elsewhere (to specialist outpatient or inpatient care).

This evidence indicates that the usual stepped care model, in which initial treatment is provided in generic CAMHS, is ineffective (due to low level of eating disorders expertise), costly (due to high rates of hospital admissions) and viewed negatively by families (due to poor continuity of care and limited expertise).

The rates of inpatient care in non-specialist and specialist care pathways and that inpatient care may account for as much 70-90% of the average cost of treatment (Byford et al 2007; Lock et al 2008) it is reasonable to assume that there are likely to be significant cost differences favouring specialist care pathways)

### *ALL AGE EATING DISORDER SERVICE*

With effect from 1 September 2017 the Clinical Commissioning Groups in Kent have commissioned North East London Foundation Trust (NELFT) to manage and deliver a new All Age Eating Disorder Service in Kent.

### *PETS PATHWAY LEGACY*

> *"If I had waited any longer for help I don't think I could have got better. I want to go to Uni and get on with my life but I can't as I have this awful thing that stops me doing anything. Now I see you I am not thinking about food all the time and there feels like there is light at the end of the tunnel. You talking to my mum has really helped me with her too. I just didn't know what to do. It's like a heroin addiction, it grips everyone. People just don't get it" – Young Person, Swale Area*

Since April 2016 the Psychoeducational Therapeutic Intervention Strategy (PETS) for Eating Disorders pilot has taken place in East and North Kent.

The success of the PETS pilot was underpinned by using an eclectic mix of therapeutic and relational approaches in parallel with the core evidence-based treatments.

By using CBT, systemic family therapy, multiple family groups, peer support and collaborative behavioural management, together with Behavioural Activation (Martell et al 2001) positive outcomes have been achieved. The pilot treated 35 patients aged between 13 and 25 with an early intervention focus; providing 20 sessions of enhanced cognitive behaviour therapy (CBT-E Fairburn 2008) whilst the families of those involved were supported as well. The pilot has now come to an end and data indicates a huge success, with many personal testimonies available to evidence the benefit the pilot has had on individuals and families.

In terms of clinical need, we had in excess of 70 referrals which was a lot more than originally forecast and took up more time than envisaged.

*"I am not eating and everything makes me sick, I vomit when I wake up and have been fainting. I went to my GP and they have referred me to KMPT, but this was a long time ago and I haven't heard a thing…I am absolutely desperate for help and it is getting worse every day"- Young person, Swale*

## *PARTNERSHIP WORKING*

Throughout the pilot Therapy Partners worked closely with a range of professionals, individuals and organisations to aid and support the recovery and transition of the young people and their families.

Partnership working consisted of the sharing of advice and information whilst collaborating on consultations and training between;

- Primary, secondary and tertiary care
- Schools, colleges and youth services
- Professional care settings delivering recognition or identification and management of eating disorders for CYP

Examples of partnership working also included referrals from GPs, schools and third sector organisations and engagement with local community mental health teams and Early Help Services.

Consultation, information, advice, and training was available for primary and secondary care clinicians, schools and colleges and youth services in order to assist in the recognition or identification and management of eating disorders.

Engagement and referrals were taken from GPs, third sector organisations, IAPT providers, local community mental health teams (children and adults) and other local Health Economy Stakeholders together with Early Help Services and School Practice Nurses. We also had a joined up working agreement with provider Addaction and their Mind and Body programme.

## *NUTRITIONISTS INPUT*

Whilst working the patients, our retained nutritional professional was able to offer help and support to our therapists by attending our supervision groups offering guidance enabling our patients to take control with gained knowledge and skills to aid their recovery, helping them restore a healthy relationship with food again.

## *THERAPISTS, TRAINING & SUPERVISION*

- *All therapists have trained in the New Maudsley Method – caring for a loved one with an eating disorder.*
- *All therapists received extensive training on outcomes, outcome tools/measures, and evaluation data.*
- *All therapists have regular ongoing Clinical supervision and CPD and an online data resource of policies and procedures risk assessments and governance documentation is available on a secure shared drive.*
- *It is our intention to offer our work to be recorded as a non-randomised clinical trial only; looking to report this in the BACP and BABCP and discussions are currently underway with the intention of publishing this once the pilot has been fully completed.*

## TARGETED SUPPORT FOR INDIVIDUALS

### *SERVICE SPECIFICATION*

**'Provide a solution focused, enhanced Cognitive Behavioural Therapy (CBT-E) (Fairburn 2008) approach to children and young people (CYP) to aid recovery, build resilience and to help CYP live their lives to the full.'**

### *POPULATION*

Secondary school age adolescents, parents, families and careers across the following NHS Clinical Commissioning Groups: Dartford, Gravesham and Swanley; Swale; Canterbury and Coastal; Thanet; Ashford; and South Kent Coast.

### *DELIVERY OF SERVICE*

**CBT-E Therapy was provided for 35 young people between the ages of 13 and 25 who met the assessment criteria. Demand for service was much higher than anticipated**.

Initially, age criteria was for 13 -18 year olds, this was extended up to age 25, in line with CYP Transformation protocols, after agreement from the CCG's.

Clinical Commissioning Groups initially commissioned a service for 29 young people; with an additional 3 young people treated through additional funding by East Kent CCG and a further 3 young people were funded via Therapy Partners. Numbers are broken down as follows:

| CCG's | Area of referral | Number of referral | Total |
|---|---|---|---|
| North Kent | DGS | 11 | 14 |
| | Swale | 3 | |
| East Kent | Ashford | 2 | 15 |
| | Canterbury | 5 | |
| | SKC | 5 | |
| | Thanet | 2 | |
| Additional East Kent CCG CYP | Ashford x2<br>Thanet x 1 | 3 | 3 |
| Additional TP funded CYP | Ashford | 2 | 2 |
| | Canterbury | 1 | 1 |
| | | | 35 |

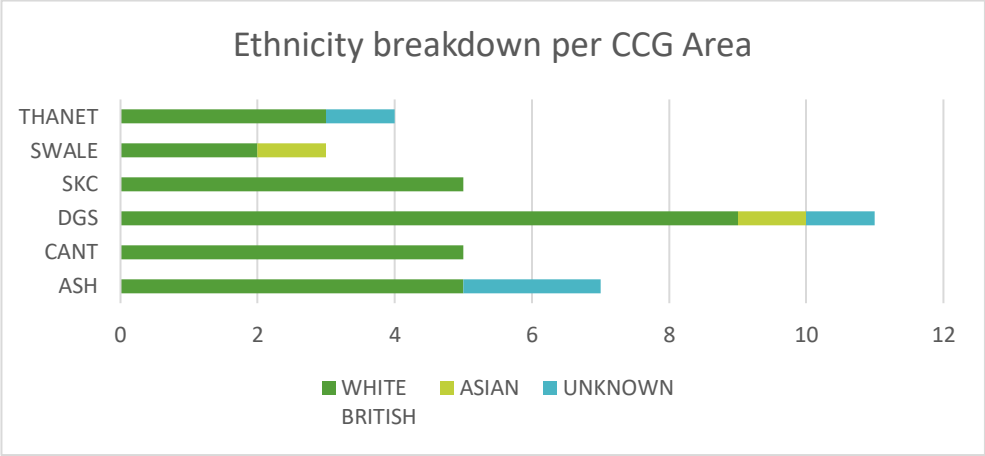
***100% of accepted referrals were contacted within 5 days and seen face-to-face within 10 days, at a venue convenient to them.***

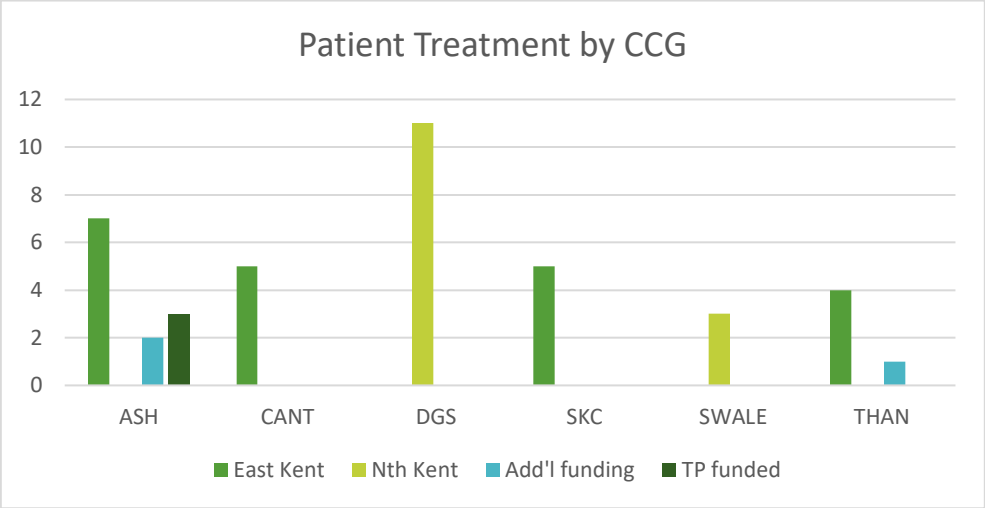
*KPI DATA*

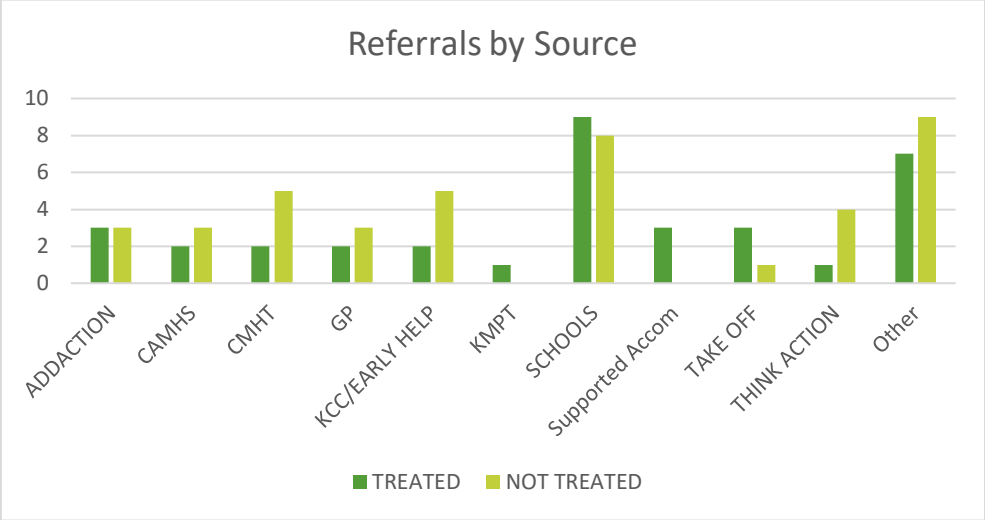
| | |
|---|---|
| Initial number of referrals | 76 |
| Number of young people entering treatment (min 25) | 35 |
| CYPs assessed* | 54 |
| Number of Young People NOT completing therapy** | 6 |
| DNA's*** | 3% |
| Number of Young People signposted**** | 22 |
| Number of referrals from CAMHS (see referrals by source graph below) | 5 |
| Percent of young people making statistically significant improvement as defined by eating disorder specific outcome measure | 80% |

*This includes CYP being referred but treatment not going ahead.
(Lack of engagement was principally due to third party requests for treatment on behalf of the young person rather than being motivated by the young person themselves)
**Four CYP who embarked on treatment did not complete as they were stepped up to CAMHS/KMPT due to risk. 2 CYP moved away (abroad (CANT) and London (SWALE) (Respectively, one maintained, the other improved into recovery).
***2 patients ended as a result of DNA's. (One after 13 sessions who had an entrenched ED and worked away a lot. The other ended after 5 sessions as the YP was ambivalent to treatment although the mother wanted treatment).
****Signposted to CAMHS and referred for support to Third Sector organisations

The above table demonstrates a reduced demand on CAMHS.
At the initial assessment of all 76 referrals Therapy Partners referred 3 CYP onwards to CAMHS and a further 4 during treatment, totally 7. Therapy Partners treated a total of 35 CYP, whose eating disorders could have ultimately led to CAMHS referrals, therefore early intervention reduced demand on CAMHS by up to 28 CYP.






## *EVALUATION METHODS*

Three types of evaluation methods were used for the programme to evidence improvements. These included the Eating Disorder Examination Questionnaire (EDE-Q) developed by Christopher Fairburn (Fairburn & Beglin 2008) and the Clinical Impairment Assessment (CIA) (Bohn & Fairburn 2008) together with a self-assessment questionnaire to determine satisfaction and perceived improvement in well-being.

Scores were taken at the start, mid and end point of treatment for both of the former measures and at the end of treatment to elicit feedback on satisfaction. A mid-treatment evaluation between therapist and young person was generally undertaken around session 7/8.

*"I feel much better about myself now and I realise that I eat unhealthily. I know what to do about it now"- Young person, Dartford*

## *OPERATIONAL OUTLINE*

Initial Assessment Criteria

- *Safe to manage as outpatients*
- *Have disordered eating patterns with significant impairment*
- *Have a BMI greater than 16*

The referrer, or young person, was contacted within a few days, an initial screening was undertaken; based on whether they had problems with eating which significantly impaired their day-to-day functioning and whether they were safe to be managed as an outpatient.

An appointment with a Therapist trained in the Christopher Fairburn protocol was made within the week, and an initial appointment was then set up at a therapeutically appropriate location e.g. at their home, school or another convenient location.

A self-assessment type of questionnaire was used by the therapist to ascertain the specific and individual problems associated with their eating problems, and to engage with the young person personally. Emphasis was placed on whether the young person was willing to engage fully in the treatment over 20 weeks.

In addition to treating the young person on a one-to-one basis receptive families were also engaged in the process incorporating the New Maudsley Method. J Treasure, U. Schmidt and P. Macdonald (2010)

Psycho-education and training workshops were offered; providing education on how to positively support a young person with an eating disorder (New Maudsley Method (2016). This included sessions on communication styles and family dynamics, if applicable. With consent school and third-sector staff were also engaged, and updated, where they had been part of the referral process. This multi-dimensional approach enhanced the general well-being of both the young person and the parent/carer in all cases.

In terms of offering a wider approach Therapy Partners engaged the services of a nutritionist. The nutritionist assisted our Therapists with advice and was also used to directly support young people where appropriate.

## *OUTCOMES & EVALUATION*

### *Clinical Impairment Assessment Scoring (CIA)*

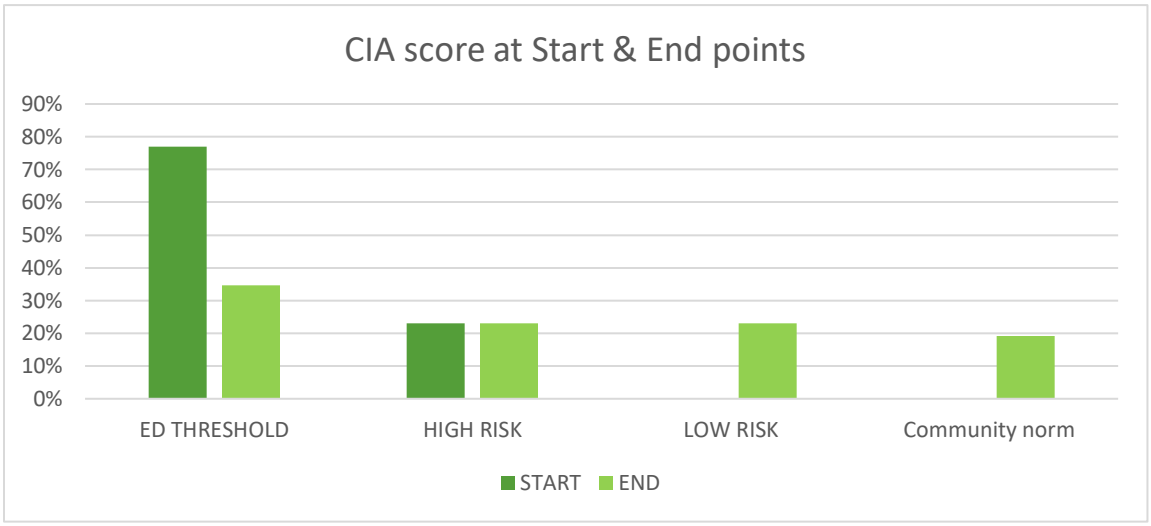
(Bohn & Fairburn 2008)

Movement between threshold categories

By benchmarking the CIA score values* to evaluate change, we were able to evidence **movement** between Eating Disorder threshold categories.
*Value categories used:

1. EATING DISORDER DIAGNOSIS values of 17.7 ± 10.7 - we have used a score of >28
2. HIGH RISK OF ONSET values of 10.6 ± 8.5 – we have used a score of >19
3. LOW RISK/COMMUNITY NORMs of 3.0 ± 3.3 (we have used <10 & < 6.5 respectively)

At the beginning of treatment 77% of our patient base was in the most severe category for impairment in daily life, with the remaining 23% belonging in the High-Risk category and showing significant impairment. None of our patient base scored in either the low risk, or community norm category, as measured at the outset of treatment.



**End of treatment results for patients who began in the highest eating disorder threshold**

| THRESHOLD | ED | HIGH RISK | LOW RISK | COMMUNITY NORM | IMPROVEMENT |
|---|---|---|---|---|---|
| % PATIENTS AT END OF TREATMENT | 40% | 25% | 10% | 25% | 60% |

By the end of treatment, of those who began in the ED threshold 60% showed improvement and only 40% remained in this category; Of those who improved, 35% moved into the low risk category and significantly 25% of patients recorded values equivalent to what would be expected in the general population, with no disordered eating

**End of treatment results for patients who began treatment in the high-risk threshold**

| THRESHOLD | ED | HIGH RISK | LOW RISK | COMMUNITY NORM | IMPROVEMENT |
|---|---|---|---|---|---|
| % PATIENTS AT END OF TREATMENT | 17% | 17% | 67% | 0% | 67% |

Of those who began their treatment in the high-risk category, 67% showed an improvement by moving into the low risk category. 17% remained stable, and 17% moved to the higher eating disorder threshold.

**Overall threshold scores**

| THRESHOLD | ED | HIGH RISK | LOW RISK | COMMUNITY NORM |
|---|---|---|---|---|
| % PATIENTS AT START OF TREATMENT | 77% | 23% | 0% | 0% |
| % PATIENTS AT END OF TREATMENT | 34% | 23% | 23% | 20% |

The overall threshold scores show a 43% decrease in patients in the eating disorder threshold. Of these, 23% moved to the low risk category and 20% to the community norm category.

CIA scoring demonstrated an 80% improvement from start to end but did not necessary show movement into another threshold. 12% of CIA scores maintained and 8% declined.

| CCG | START | MID | END | SCORES | THRESHOLD |
|---|---|---|---|---|---|
| ASH | 29 | 10 | 2 | IMPROVED | Community norm |
| ASH | 18 | 18 | 12 | IMPROVED | LOW RISK |
| THA* | 36 | 26 | 3 | IMPROVED | Community norm |
| ASH | 41 | 39 | 38 | IMPROVED | ED THRESHOLD |
| ASH | 37 | 40 | 47 | DECLINED | ED THRESHOLD |
| CANT | 36 | 25 | 16 | IMPROVED | LOW RISK |
| CANT | 37 | 39 | 4 | IMPROVED | Community norm |
| CANT | 29 | 27 | 29 | MAINTAINED | ED THRESHOLD |
| CANT | 23 | 24 | 13 | IMPROVED | LOW RISK |
| DGS | 48 | 24 | 30 | IMPROVED | ED THRESHOLD |
| DGS | 18 | 16 | 14 | IMPROVED | LOW RISK |
| DGS | 33 | 30 | 26 | IMPROVED | HIGH RISK |
| DGS | 40 | 31 | 30 | IMPROVED | ED THRESHOLD |
| DGS | 29 | 26 | 3 | IMPROVED | Community norm |
| DGS | 20 | 22 | 26 | MAINTAINED | HIGH RISK |
| DGS | 32 | 26 | 4 | IMPROVED | Community norm |
| DGS | 40 | 35 | 37 | IMPROVED | ED THRESHOLD |
| SKC | 45 | 40 | 27 | IMPROVED | HIGH RISK |
| SKC | 26 | 44 | 45 | DECLINED | ED THRESHOLD |
| SKC | 47 | 47 | 45 | MAINTAINED | ED THRESHOLD |
| SKC | 38 | 25 | 22 | IMPROVED | HIGH RISK |
| SKC | 32 | 34 | 25 | IMPROVED | HIGH RISK |
| SWA | 17 | 11 | 11 | IMPROVED | LOW RISK |
| SWA | 45 | 40 | 32 | IMPROVED | ED THRESHOLD |
| SWA | 33 | 26 | 21 | IMPROVED | HIGH RISK |
| ASH | 30 | 18 | 18 | IMPROVED | LOW RISK |

*Thanet referrals total of 4. 3 referrals completed treatment, 1 referred on. Data incomplete for 2 CYP who completed therapy due to therapist hospitalization.

## CIA Scoring Evaluation

| | DECLINED | MAINTAINED | IMPROVED |
|---|---|---|---|
| DGS | 0% | 12.5% | 87.5% |
| SWALE | 0% | 0% | 100% |
| CANTERBURY | 0% | 25% | 75% |
| ASHFORD | 20% | 0% | 80% |
| SKC | 20% | 20% | 60% |
| THANET* | 0% | 0% | 100% |
| **TOTAL** | **8%** | **12%** | **80%** |

*Thanet referrals total of 4. 3 referrals completed treatment, 1 referred on. Data incomplete for 2 patients who completed therapy due to therapist hospitalization.

**Percentage of young people moving to recovery as defined by eating disorder specific outcome measure questionnaire: 96%**

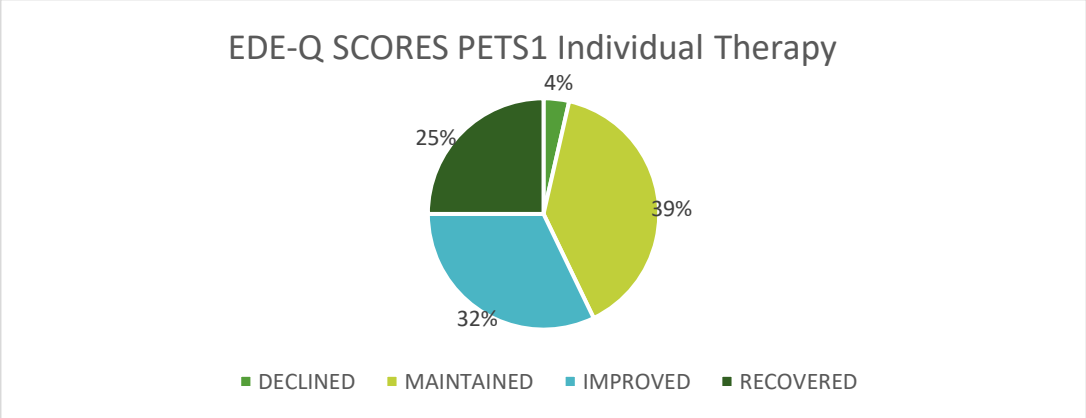
*EDE-Q Data*

Using the EDE-Q measure 57% of young people have improved; with 25% of these reducing to what is considered the community norms on global scoring (1.55).

It should be noted that 72% of the 'recovered' show a correlation with lower initial scores and would support the case for early intervention. Only 4% declined.

| | DECLINED | MAINTAINED | IMPROVED | RECOVERED |
|---|---|---|---|---|
| **DGS** | 11% | 33% | 44% | 11% |
| **SWALE** | 0% | 33% | 0% | 67% |
| **CANTERBURY** | 0% | 40% | 40% | 20% |
| **ASHFORD** | 0% | 60% | 20% | 20% |
| **SKC** | 0% | 40% | 40% | 20% |
| **THANET** | 0% | 0% | 0% | 100% |
| **TOTAL** | **4%** | **39%** | **32%** | **25%** |

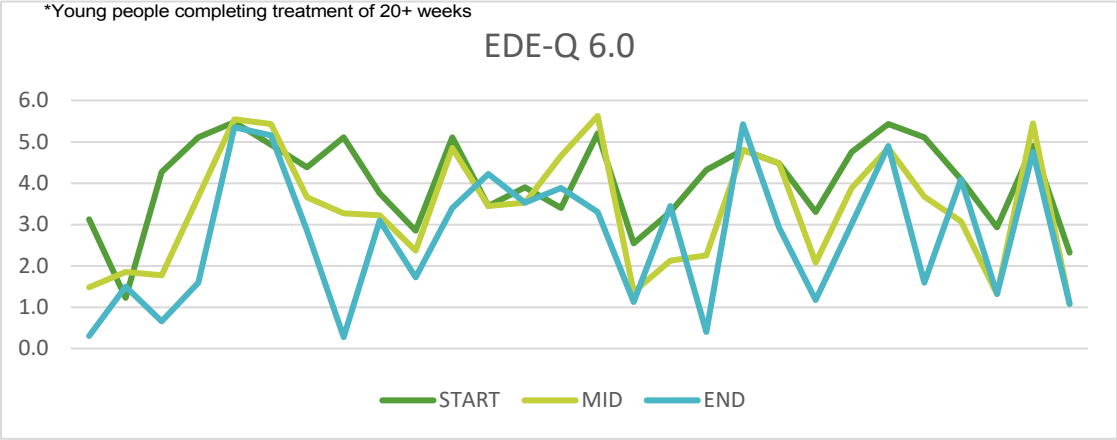
**As evidenced from the table, 96% of those treated either recovered, improved or maintained their current status. Overall, 57% improved & 25% recovered to community norms.**




25% OF EDE-Q scores reduced to a point that is considered the community norm on global scoring (1.55). It should also be noted that 72% of these 'recovered' cases show a correlation with lower initial scores which strongly supports the case for early intervention.

| CCG AREA | START | MID | END | SCORES |
|---|---|---|---|---|
| ASH | 3.1 | 1.5 | 0.3 | RECOVERED |
| ASH | 1.2 | 1.9 | 1.5 | MAINTAINED |
| THA | 4.3 | 1.8 | 0.7 | RECOVERED |
| ASH | 5.1 | 3.7 | 1.6 | IMPROVED |
| ASH | 5.5 | 5.6 | 5.4 | MAINTAINED |
| ASH | 4.9 | 5.4 | 5.2 | MAINTAINED |
| CANT | 4.4 | 3.7 | 2.9 | IMPROVED |
| CANT | 5.1 | 3.3 | 0.3 | RECOVERED |
| CANT | 3.8 | 3.2 | 3.1 | MAINTAINED |
| CANT | 2.9 | 2.4 | 1.7 | IMPROVED |
| DGS | 5.1 | 4.9 | 3.4 | IMPROVED |
| DGS | 3.5 | 3.1 | 2.6 | IMPROVED |
| DGS | 3.9 | 3.4 | 3.2 | MAINTAINED |
| DGS | 4.3 | 4.5 | 4.0 | MAINTAINED |
| DGS | 5.2 | 4.7 | 3.3 | IMPROVED |
| DGS | 2.6 | 1.4 | 1.1 | RECOVERED |
| DGS | 3.3 | 2.1 | 3.5 | MAINTAINED |
| DGS | 4.3 | 2.3 | 0.4 | IMPROVED |
| DGS | 4.8 | 4.8 | 5.4 | DECLINED |
| CANT | 4.5 | 4.5 | 4.0 | MAINTAINED |
| SKC | 3.3 | 2.1 | 1.2 | RECOVERED |
| SKC | 4.8 | 3.9 | 3.0 | IMPROVED |
| SKC | 5.4 | 4.9 | 4.9 | MAINTAINED |
| SKC | 5.1 | 3.7 | 1.6 | IMPROVED |
| SKC | 4.1 | 3.1 | 4.1 | MAINTAINED |
| SWA | 2.9 | 1.3 | 1.3 | RECOVERED |
| SWA | 4.9 | 5.5 | 4.8 | MAINTAINED |
| SWA | 2.3 | 1.1 | 1.1 | RECOVERED |

| | |
|---|---|
| 4.1-6.0 | HIGHER SCORES |
| 3.1 – 4.0 | MID SCORES |
| 1.6 – 4.0 | LOWER SCORES |
| **<1.55** | **COMMUNITY NORMS** |




*Improvement in Emotional Wellbeing*

Improvement in emotional wellbeing was gauged through end of treatment questionnaire responses. Results indicated that 60% of those treated had an overall improved mental wellbeing

| | DECLINED | MAINTAINED | IMPROVED | REFERRED ONWARDS/UNCLASSIFIED |
|---|---|---|---|---|
| **DGS** | 0% | 9% | 64% | 27% |
| **SWALE** | 0% | 0% | 100% | 0% |
| **CANTERBURY** | 0% | 40% | 60% | 0% |
| **ASHFORD** | 14% | 29% | 57% | 0% |
| **SKC** | 20% | 20% | 60% | 0% |
| **THANET** | 0% | 0% | 50% | 50% |
| **TOTAL** | **6%** | **17%** | **60%** | **17%** |

## *OVERALL CBT-E OUTCOMES PER PATIENT*

| ETHNICITY | CCG AREA | STATUS | STARTED | ENDED | RECOVERY STATUS |
|---|---|---|---|---|---|
| **WB** | THAN | COMPLETE | Feb-17 | Jun-17 | IMPROVED |
| **WB** | ASH | COMPLETE | Feb-17 | Jul-17 | IMPROVED |
| **WB** | ASH | COMPLETE | Jan-17 | Jun-17 | IMPROVED |
| **WB** | ASH | ENDED | Mar-17 | Mar-17 | MAINTAINED |
| **WB** | ASH | ENDED | Mar-17 | Apr-17 | MAINTAINED |
| **WB** | ASH | COMPLETE | May-17 | Jul-17 | IMPROVED |
| **WB** | ASH | COMPLETE | Nov-16 | Jul-17 | IMPROVED |
| **WB** | ASH | COMPLETE | Nov-16 | Jul-17 | DECLINED |
| **WB** | CANT | COMPLETE | Jul-16 | Jul-17 | IMPROVED |
| **WB** | CANT | COMPLETE | Aug-16 | Jul-17 | IMPROVED |
| **WB** | CANT | COMPLETE | Jan-17 | Apr-17 | MAINTAINED |
| **WB** | CANT | COMPLETE | Jan-17 | Jul-17 | IMPROVED |
| **WB** | CANT | COMPLETE | Aug-17 | Mar-17 | MAINTAINED |
| **WB** | DGS | COMPLETE | Aug-16 | Jan-17 | IMPROVED |
| **WB** | DGS | COMPLETE | Aug-16 | Mar-17 | IMPROVED |
| **A** | DGS | COMPLETE | Sep-16 | Jun-17 | IMPROVED |
| **WB** | DGS | ENDED | Oct-16 | Nov-16 | REFERRED |
| **WB** | DGS | ENDED | Nov-16 | Jan-17 | REFERRED |
| **WB** | DGS | COMPLETE | Jan-17 | Jun-17 | IMPROVED |
| **WB** | DGS | ENDED | Aug-16 | Nov-16 | REFERRED |
| **WB** | DGS | COMPLETE | Mar-17 | Jun-17 | IMPROVED |
| **WB** | DGS | COMPLETE | Feb-17 | Jun-17 | MAINTAINED |
| **WB** | DGS | COMPLETE | Feb-16 | Jun-17 | IMPROVED |
| **WB** | DGS | COMPLETE | Jan-17 | Jun-17 | IMPROVED |
| **WB** | SKC | COMPLETE | Jan-17 | Jun-17 | IMPROVED |
| **WB** | SKC | COMPLETE | Jan-16 | Jun-17 | DECLINED |
| **WB** | SKC | COMPLETE | Dec-16 | Jul-17 | MAINTAINED |
| **WB** | SKC | COMPLETE | Nov-16 | May-17 | IMPROVED |
| **WB** | SKC | COMPLETE | Dec-16 | May-17 | IMPROVED |
| **WB** | SWALE | COMPLETE | Nov-16 | Mar-17 | IMPROVED |
| **A** | SWALE | COMPLETE | Sep-16 | Apr-17 | IMPROVED |
| **WB** | SWALE | COMPLETE | Nov-16 | Jun-17 | IMPROVED |
| **WB** | THAN | ENDED | Aug-16 | Sep-16 | REFERRED |
| **WB** | THAN | COMPLETE | Nov-16 | Jan-17 | Pending |
| **WB** | THAN | COMPLETE | Dec-16 | Jul-17 | Pending |

## *ASSESSMENT OF RESULTS*

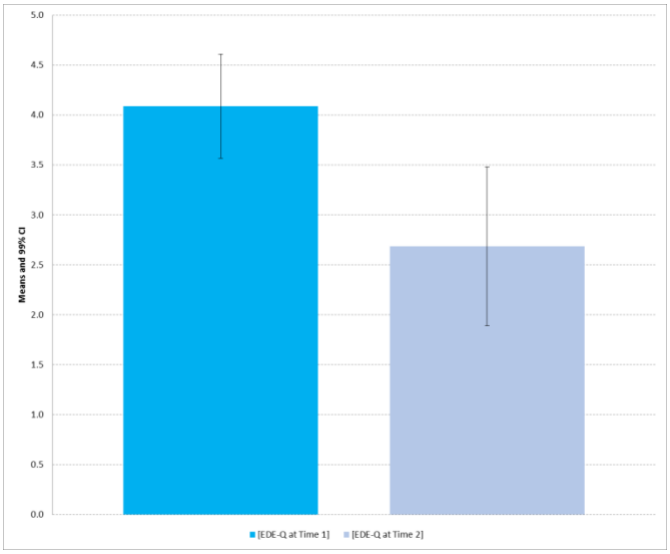
The following analyses have been conducted on a sample size of 28 as some patients did not participate in the CIA and EDE-Q questionnaire, using the Outcome Measures Sheet developed by the Child Outcomes Research Consortium (CORC).

Analyses have been conducted for each measure used within the PETS project, at time one and time two; the start and end of treatment, by a KCC Analyst for Children and Young People's Mental Health Transformation.

The graphs below display the average scores for people receiving treatment at time one and time two. The error bars represent the confidence intervals around the means. The confidence interval, or margin of error, gives a range of numbers which we are reasonably certain contains the true average. If the interval is narrow, we are quite certain what the true average is. If it is wide, we are not. As a rough rule, if the difference between two averages is within the margin of error, there is no cause to think that the two averages are different. However, if the difference is larger than the margin of error, we may want to investigate why there may be a difference between the two figures.

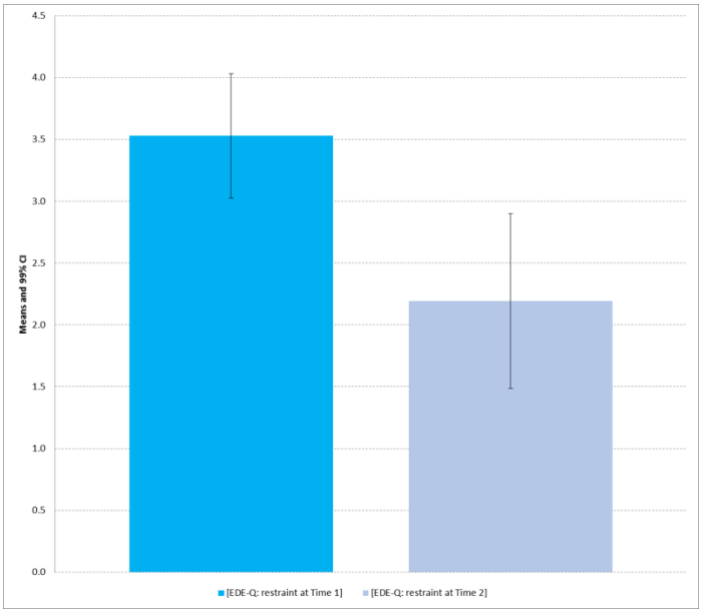
### *Eating Disorder Examination Questionnaire (EDE-Q )*

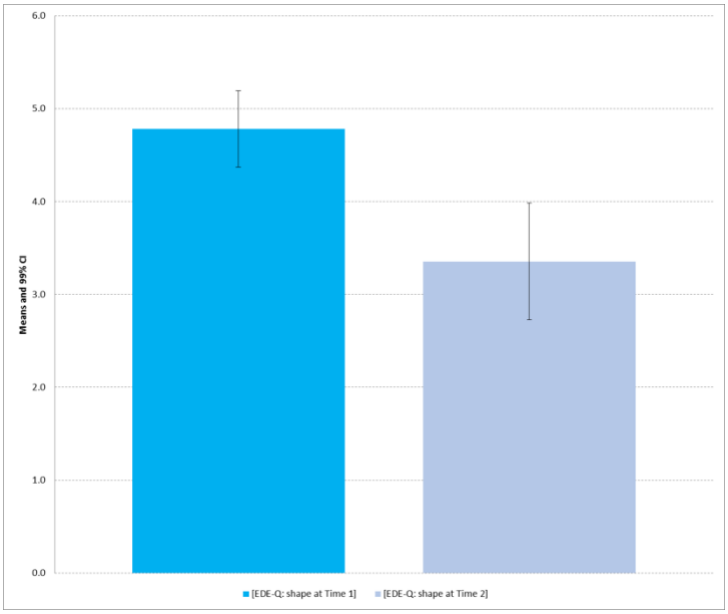
At time one, the average EDE-Q score was 4.09. By the end of treatment, this had decreased significantly (99% CI) by 1.40 points to 2.69.



### *EDE-Q: Restraint*

At time one, the average EDE-Q restraint domain score was 3.53. By the end of treatment, this had decreased significantly (99% CI) by 1.34 points to 2.19.



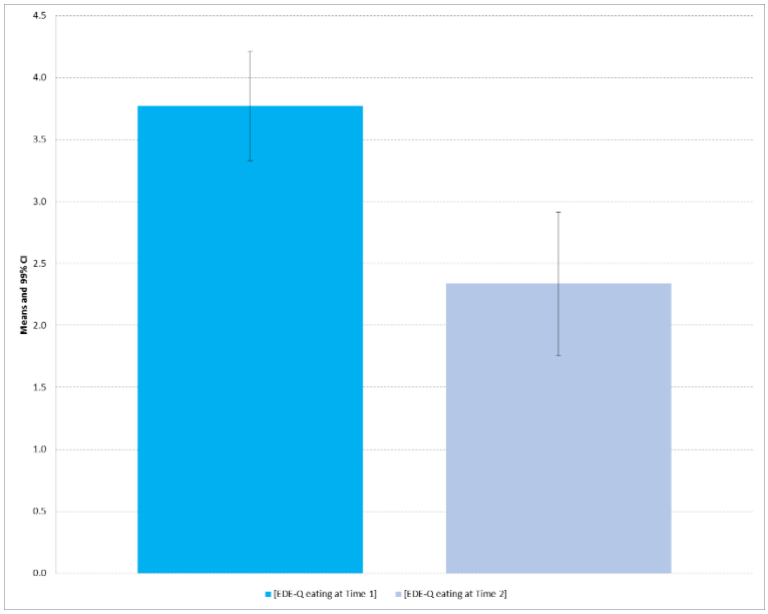




### *EDE-Q: Shape*

At time one, the average EDE-Q shape domain score was 4.78. By the end of treatment, this had decreased significantly (99% CI) by 1.43 points to 3.35.

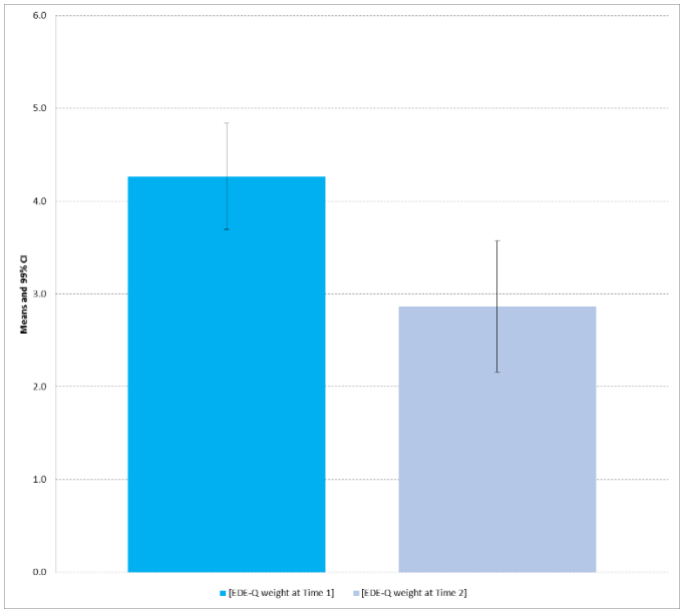
### *EDE-Q: Eating*

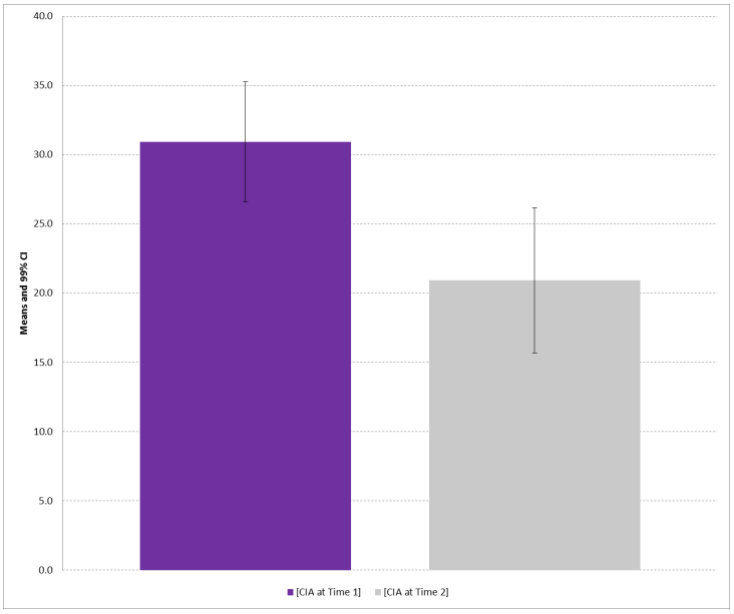
At time one, the average EDE-Q eating domain score was 3.77. By the end of treatment, this had decreased significantly (99% CI) by 1.44 points to 2.34.



### *EDE-Q: weight*

At time one, the average EDE-Q weight domain score was 4.26. By the end of treatment, this had decreased significantly (99% CI) by 1.40 points to 2.86.




### *Clinical Impairment Assessment Questionnaire (CIA)*

At time one, the average CIA score was 30.91. By the end of treatment, this had decreased by 9.99 points to 20.92. This decrease was not significant (95% CI).

### *RECOMMENDATIONS AND FEEDBACK*

One significant learning insight has been that successful outcomes and completion of treatment, depend upon accurately gauging the young person's commitment to treatment, rather than perhaps parent/carer or school staff members' instruction and concern. Successful outcomes and completion of treatment were shown to be positively correlated to the young person's direct level of engagement and motivation. Therapy Partners would recommend that motivation and engagement are expressly evaluated both at assessment and also at a review point some 5-8 sessions into treatment in order to maximize allocation of therapy sessions.

Meeting the young person locally helped with engagement and satisfaction.

Better outcomes were achieved through a multi-dimensional approach, engaging with families, schools and third sector staff to enhance the general well-being of both the young person and the parent/carer in all cases.

Offering support as a small, local organisation, allowed Therapy Partners the flexibility to act swiftly where required, enabling a family centric individual approach; ultimately removing some of the barriers to recovery.

In total 35 young people were treated across North and East Kent on a one-to-one basis. Demand for the service, particularly from the Ashford and surrounding areas, was much higher than anticipated. Complex co-morbidities were present in the majority of entrenched cases.

A family centric approach is further recommended and endorsed by way of this example: one person receiving one-to-one support was part of a family where all members had experienced severe trauma and loss, together with financial difficulties. By working alongside local charities and writing to this particular family's landlord, imminent eviction from the family home was averted, thereby directly removing a major cause of distress. (see appendices)

Fairburn (2008) recommends a post treatment review at 20 weeks, however Therapy Partners introduced this at 12 weeks in order to include in our evaluation. Outcomes have been favourable with some indications that treatment improvement has continued after treatment ended. In North Kent CCG area Therapy Partners have been running post-treatment peer support groups in line with PETS2. These have been well received by patients.

Less social isolation and improved close relationships were cited by the majority of participants with some people returning to university and gaining employment. A number of patients have since become actively involved in our Rewrite-your-story charity, which is testament to the improved well-being and engagement experienced as a result of taking part in the pilot.

A further recommendation would be to offer peer support groups to individuals completing one-to-one therapy: as a follow-on support mechanism.

In terms of annexing strategy both in the North and East Kent, Therapy Partners have been trialing the use of both telephone and online support particular patients that had difficulty in attending the face-to-face sessions which has been successful.

One patient with whom we had had successful outcomes from individual therapy was lucky enough to secure her dream job as cabin crew for a well-known airline. This meant that she was unable to attend regular face-to-face sessions, but after re-contracting and agreeing the boundaries we started some online support for this young person while she was undergoing training in London. This patient's feedback is as follows:

*"The online support was really helpful and meant I could access my therapist L just to talk through issues that may have arisen and I would like to thank Therapy Partners for working in a way that is flexible and it really helped me"- Young person, Thanet*

### *Isolation – A Recurring Theme*

The common theme of those in therapy was how isolated they felt from their school, college or university community, classmates and friends, causing them to miss classes. They also felt isolated and detached as they felt their friends did not understand. It is important to remember that eating disorders may naturally isolate individuals as their thought processes, day and life structure become overtaken by obsessing about food, calorie counting, over-exercising, leaving little space for relationships and other interests.

The individuals in therapy asked if it was possible to meet other people, who were experiencing similar issues which was facilitated where possible.

## SUPPORT GROUPS FOR PARENTS AND CARERS

### *SERVICE SPECIFICATION*

**'Provide facilitated peer support groups for parents and carers of CYP with ED using a psychoeducational approach to enable understanding of the key themes of ED, build resilience, and lessen the adverse impact ED has on families.'**

### *DELIVERY OF SERVICE*

Therapy Partners used systemic therapy methods within a psychoeducational setting, working to foster resilience and understanding within the families and individuals who support the young person with an eating disorder.

Individuals in therapy enquired about the possibility of meeting others experiencing similar issues to combat the feeling of loneliness and isolation, a common theme that ran throughout individual therapy sessions, therefore we ran four peer support sessions, 2 in each locality. These groups held a maximum of eight people and were carefully managed. The groups' brief was not to talk about food and Eating Disorders due to a competitive element present in the illness, but rather to discuss emotions, families, and emotional intelligence strategies. The name EAT (Emotions and Thoughts) were devised for these groups.

| Area | Type of session | DGS | SWALE | TOTAL |
|---|---|---|---|---|
| **NORTH KENT** | One to one family support sessions | 17 | 1 | 18 |
| | Peer support group sessions for service users | 1 | 1 | 2 |
| | Training sessions offered for family members | 0 | 1 | 1 |

| Area | Type of session | ASHFORD | CANTERBURY* | SKC | THANET | TOTAL |
|---|---|---|---|---|---|---|
| **EAST KENT** | One to one family support sessions | 7 | 0 | 15 | 12 | 34 |
| | Peer support group sessions for service users | 1 | 0 | 0 | 1 | 2 |
| | Training sessions offered for family members | 2 | 0 | 1 | 1 | 4 |

*parents/carers of the patients from Canterbury were not engaged due to living arrangements or client wishes.

## *EVALUATION METHODS*

Progress was viewed in terms of the development of communication systems and interaction between each person in the family or relationship and their levels of personal wellbeing. End of therapy feedback and questionnaires were used to evaluate the benefit of the peer support groups.

> *"It's amazing. I don't feel like I am the only one. I can see that I'm not a failure by getting this, anyone can and for so many reasons. I love the fact that my voice is being heard. Why should I be ashamed or feel guilty?"– Peer support group member, DGS*

## *OPERATIONAL OUTLINE*

In terms of engagement with families and for Therapy Partners to provide a truly person-centred approach to provide therapy locally. Many assessments and interventions were also made at the young person's home. At this stage, we also consulted with the young person's family members and carers, and it became evident that there were mixed and conflicting feelings regarding the young person in question.

At these assessments, we provided an initial overview of the therapy and what was available in terms of support for the families. Some families were ambivalent, others embraced the concept of support and following this feedback, Therapy Partners offered a two-faced approach to the support groups. Some families wanted individual support on a one-to-one basis which was offered together with some family group work. Family groups work consisted of combinations of family members e.g. mother and daughter, mother, father and daughter, mother, father, daughter, and siblings. On some occasions grandparents and other extended family members were included.

Following on from the assessments, and from the feedback obtained, Therapy Partners took the opportunity to offer flexibility as this made it easier for people to engage. Following extensive feedback from families we also offered support to other family members alongside individual sessions on a one-to-one basis with either mums' and dads' or brothers and sisters. Other family members were contacted towards the end of the Young Person's Therapy and family support was provided for a number of families by offering a menu of support services for families ranging from attending awareness training alongside professionals, to providing one-to-one, family and group support.

Young people with lived-experience were employed to help deliver the training and also to provide group facilitation where more than one family were involved.

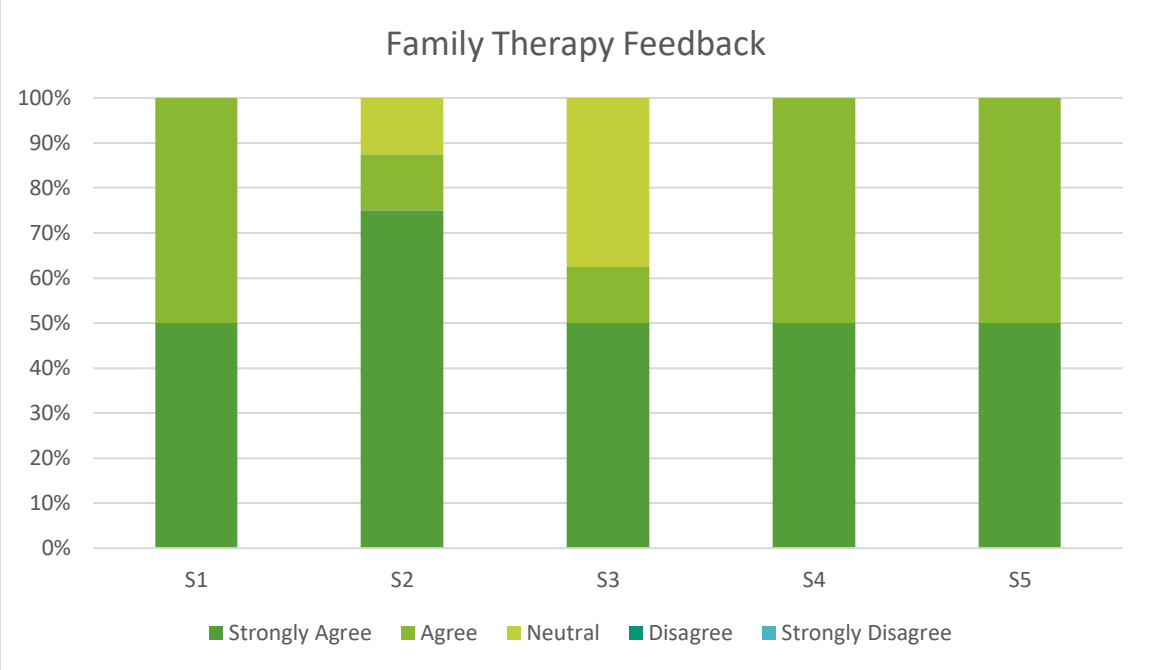
Positive outcomes were shown where a combination of one-to-one sessions of family support, together with attendance at awareness training and/or group support were employed.

This pluralistic approach was therefore beneficial to families and carers.

## *RESULTS AND RECOMMENDATIONS*

Patients and their families identified that learning outcomes from support included;

- Better understanding of how their family functions
- The ability to identify strengths and weaknesses within their own family system
- Setting goals and devising their own strategies to resolve problems
- Developing communication skills, facilitating open conversation between family members.
- Strengthening of the family unit




The feedback graph above is broken down in to % of responses for each of the following statements;

Statement 1: We have a better understanding of how our family functions
Statement 2: We have the ability to identify strengths and weaknesses within our own family system
Statement 3: We are able to set goals and devise our own strategies to resolve problems
Statement 4: Our family communication skills have developed, facilitating open conversation between family members.
Statement 5: Our family unit has been strengthened

Although peer support groups have proven to be beneficial in enhancing personal wellbeing for those who participated, and represent an ideal way to support a young person with an eating disorder, geographical challenges arose when attempting to organise suitable locations impacting on attendance for all.

Pragmatically, the peer group support represented a stepped-down level of support which proved useful for the families and young person and more cost effective than one-to-one work.

> *"Without Therapy Partners, I would have no support for our problems because other services I've been referred to haven't offered anything"- Mum, Ramsgate*

### *LEARNING AND EVALUATION OUTCOMES*

In terms of the Family Support we used systemic therapy methods, which is an approach that works with families and those who are in close relationships to foster change. These changes are viewed in terms of the systems of interaction between each person in the family or relationship. Following on from our support and from feedback obtained patients identified that learning outcomes from support were;

- They had a better understand of how their family functions
- They could identify strengths and weaknesses within their own family system.
- They could now set goals and devise strategies to resolve problems
- The communication skills are developed and family members were talking to each other and many felt this has made their entire family unit stronger
- This pilot identified a need for Family Therapy, Peer Support for family members, and further training sessions.
- The families we have supported will not 'fix' themselves overnight and we have been asked for continued support and help, way above what we were funded to do. The family needs to be treated as a whole whereas at the moment they are either just surviving or accessing GPs for medication and IAPT therapies. The feedback we have is that medication and IAPT doesn't change what is happening in the family.
- There have also been criticisms about waiting times for treatment, with more than one family in a similar situation

## *PSYCHO/SOCIAL EDUCATION GROUPS*

| Group | Total |
|---|---|
| **Parents, Carers, Professionals** | **83** |
| **One to one family support sessions (18 in North Kent, 30 in East Kent)** | **48** |
| **Referrals received from schools (Homewood, Langton, Ursline, Highworth Grammar)** | **9** |
| **Percentage of families who completed the program** | **100%** |
| **DNA's** | **3** |
| **Number of individuals who accessed online support and video** | **3380** |

## *OVERVIEW OF SUPPORTED FAMILIES*

The families we have supported have had a much higher need than first anticipated. The majority of the families displayed these common negative themes: chaotic, dysfunctional, from separated families, history of abuse, children from parents who had been in the care system, other presenting mental health conditions - such as severe anxiety and depression, and in the majority of the other family members and parents their care methods maintain the Eating Disorder.

The other (perhaps seen as positive) common themes were: high achieving families (with children often from grammar schools), children who were high achieving, academic, creative (dancers, artists, drama students), and competitive. The common denominator in all of the families was the economic impact the ED has had. Examples of this include students who get into significant debt due to spending all their money on food and thus not being able to attend University any longer, parents changing role, reducing hours, or giving up work all together to care for the person with the ED, and the sheer cost of buying food in order to either try and tempt anorexics to eat or to replace all of the missing food every few days with a person with bulimia.

Please refer to case study of family A in appendices.

*"Without Therapy Partners, I would have no support for our problems, because other services I've been referred to haven't offered anything"- Mum of service user, Ramsgate*

## AWARENESS TRAINING

*"I work with a woman who is suffering with Anorexia Nervosa & following the course I have been conscious of my actions and re-acting accordingly. This is proving to have a positive effect on our relationship. I have ordered the book which you advised and this should be arriving shortly" - Carers Organisation Social Inclusion coordinator*

### *SERVICE SPECIFICATON*

**"To develop awareness training among school counsellors, teachers and teaching assistants around eating disorders"**

**'Equip carers with the skills and knowledge needed to support and encourage children and young people and help prevent barriers to recovery.'**
**'Enhancing emotional intelligence in the client's families whilst improving social and human factors'**

**'Increase awareness amongst school staff and equip them with the knowledge to support them to identify students who may have an eating disorder'**

### *DELIVERY OF SERVICE*

A total of 83 people attended the awareness training across Kent, with a split of 43 in East Kent and 40 in North Kent. The audience consisted of:

- *Parents and carers*
- *Third sector organisations*
- *School staff*


Therapy Partners' training course contains a summary of the main themes around eating disorders looking at the style of carers and traps that people fall into which actually maintain the patterns of dysfunctional behaviour in an eating disorder. It is based on the New Maudsley method training developed by Treasure et al (2007) focusing on the main themes surrounding eating disorders.

### *COURSE OUTLINE*

- *What is an eating disorder? – A summary.*
- *Who gets an eating disorder and why?*
- *What type of carer are you, what is your automatic 'go to style' when supporting someone?*
- *Traps we all fall in when working with an individual with an ED that actually maintain the patterns of behaviours in an Eating Disorder.*
- *How to adapt your behaviours and carer/supporting style to best support a young person with an Eating Disorder.*

Due to difficulties with engaging with professionals and schools, a **psychoeducational video** (see section below) was created to reach a much wider audience**.** This was a slight adaptation of the original scope of an online course, and was agreed with CCG's in advance.

### *EVALUATION METHODS*

A training evaluation questionnaire was used to ascertain the training outcomes, including raised awareness, understanding of eating disorders, the ability to identify someone with disordered eating, and local signposting information.

### *OPERATIONAL OUTLINE*

We contacted 67 of the schools within the pilot area, to help assess the need for training around eating disorders, in order to help us commission a psycho- educational video. We asked teachers and classroom assistants what they thought would be helpful and beneficial, in terms of providing a training medium that would be viewed online.

At the start of the PETS pilot we assumed that most our referrals would come from schools. As the program progressed, it became evident that this would not be the case.

Schools were difficult to engage with in the first instance, with low response rates to written correspondence regarding the PETS pilot. This was mainly due to the fact that educational extra-curricular timetables are often scheduled by the school a year in advance; therefore organising additional events at short notice can become problematic.

As a result, we arranged face-to-face meetings with school staff, which had a higher success rate of creating opportunities to deliver training. Training was carried out in two schools; one in North Kent the other in East Kent. Training days were scheduled during School Inset Days which did not disrupt the normal timetable. The training was well received.

Individuals of school age start to experience a dip in academic studies and/or their behavior due to abnormal brain patterns caused by disordered eating.

This fact enabled Therapy partners to engage well with schools, as the PETS goal of enhanced student wellbeing would have a positive effect on the academic performance of the individuals, therefore improving the performance of the school as a whole.

As a result of CCG colleagues' input, Therapy Partners decided to review the current methods of engagement and the effectiveness of the training model.
Consultation took place with other healthcare professionals, colleagues at KCC early help and third sector organisations, and it was agreed to develop additional training for professionals and to invite pastoral care leads and school support staff to attend the training, which proved an effective way to encourage school's engagement.

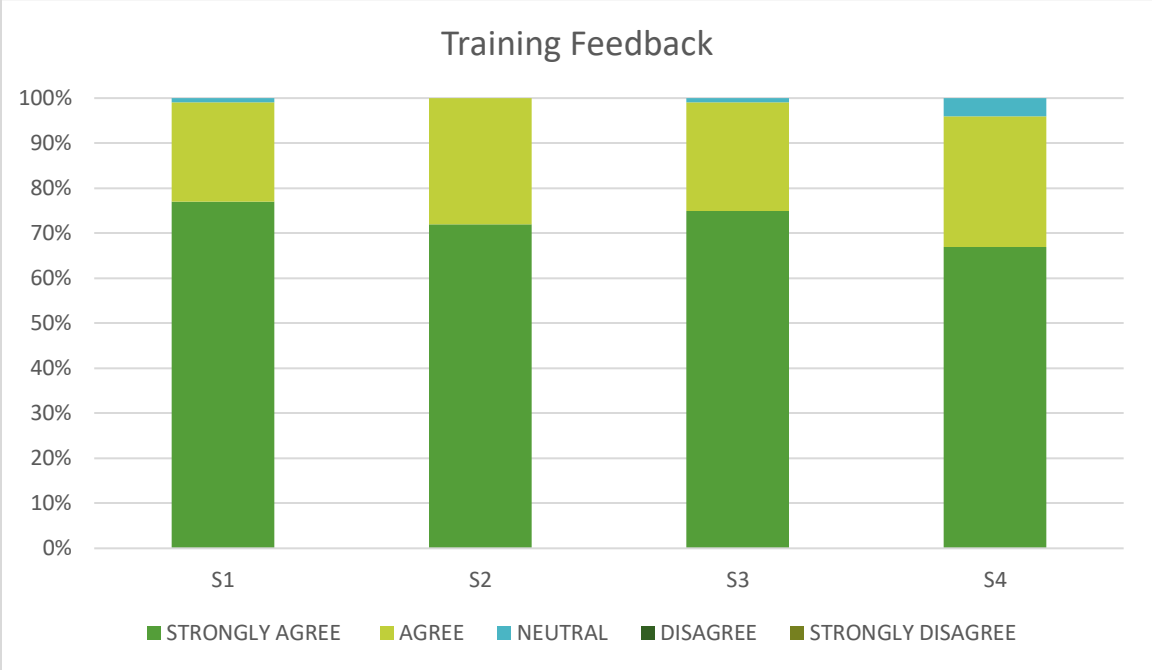
Training for professionals, although not included in the PETS pilot service specification, was introduced as a way of raising awareness and proved to be a cost effective method for providing training in schools. The training was adapted when increasing numbers of people in therapy asked to come to the sessions. The training was focused on how to support people with an eating disorder and the mixed groups in the sessions have worked exceptionally well.

## *RESULTS AND RECOMMENDATIONS*

**100% of those who attended training rated it good or higher, with 83% of participants rating it as excellent.**

96% of Participants felt they would be able to apply the knowledge gained from the professional training, demonstrating a reduced stigma for mental health.

*"I felt like I'd struck gold when I went to your training. I can't thank you enough. I'd realised that I'd been doing everything the wrong way. Now I have a structure to work with"- Training Attendee currently supporting young person with an ED in supported housing.*




The feedback graph above is broken down in to % of responses for each of the following statements;

Statement 1: The content of the training was organized and easy to follow.
Statement 2: The training objectives and topics were followed.
Statement 3: The training met my expectations.
Statement 4: I feel I will be able to apply the knowledge I have learnt.

*"I found the training informative and an enjoyable session the lived experience and the information I gained will really help me with my work supporting young people"- Support Worker, Children's Charity*

***Feedback from Professional's Training***

***"I would like to say how much I enjoyed the course that you covered on Monday afternoon. I work with a woman who is suffering with Anorexia Nervosa & following the course I have been conscious of my actions and re-acting accordingly. This is proving to have a positive effect on our relationship. I have ordered the book which you advised and this should be arriving shortly"- Social Inclusion Coordinator***

***"I found the training informative and an enjoyable session the lived experience and the information I gained will really help me with my work supporting young people"- Support Worker, Children's Charity***

***"I just wanted to thank you for today's session, it was extremely informative and very helpful. The training was brilliant and I really feel I have taken a step in the right direction in terms of support for my Daughter. I was so overwhelmed today with the training and support your organisation offers I just had to say a big fat thank you"- Mother of young person with an eating disorder***

Organisations who have delegates that attended the training include:

*Circle housing*
*Carers Ashford*
*Young Healthy Minds*
*Dartford Council*
*Riverside*
*Avondale Care*
*Dartford CMHT*
*CXK*
*Self-Horizons*
*SOBBS*
*KMPT*
*KCC EHPS*
*DWP*
*Amicus Horizon*
*Think Action*
*Centra Care*
*Insight*
*Porchlight*
*Social Services*
*Swale CMHT*
*Low cost counselling providers*
*Highworth Grammar School*
*Homewood School*
*Social Enterprise Kent*

## PSYCHOEDUCATIONAL VIDEO

**In terms of education and raising awareness a psychoeducational video was created to reach a wider audience.**

Feedback was received throughout the project indicating the need for an educational video raising awareness of eating disorders. It was to feature young people with lived-experiences as this would engage and resonate with both those seeking support and professionals alike.

The campaign highlighted within the video **'Rewrite Your Story'** promotes a positive message regarding recovery from eating disorders. The website, **www.rewriteyourstory.org.uk**, was developed to contain valuable information both to raise awareness and to act as signpost for those seeking support.

The video has currently received over 3,000 views via Facebook and can be found on the Therapy Partners website. It was and is shown at training and awareness events run by Therapy Partners.

> *"I think it is powerful, obviously using real life examples will resonate with young females and they are very honest as to their individual issues, etc. I like the length (10 mins) long enough to get the message across but not too long so as to lose focus, very professionally done as well" - Mental Health Professional, East Kent, February 2017*

***The video has signposted 3,381 people on Facebook.***

In addition to having access to a video, many professionals and parents wanted a resource that they could access easily, ideally via the Internet, containing some factual information and places to signpost young people to. This feedback was included in the commissioning process.

Professionals said it would be good to hear from young people themselves as 'people buy people'. As young people are true experts in their own lives and their eating disorders, we wanted them to be the focus of the video and the subsequent website. This led us to naming the video rewrite your story to act as inspiration. The young people in the video were very creative and artistic and became the focus of a positive message that recovery was possible. Both Ruby and Sara wanted to produce a graphic by way of a legacy which we could use for a website banner. Time-lapse photography showing the creative process was used to showcase the powerful banner head-line of rewrite your story on the new website.

Following on from our research and as a result of working with our video production company, the original brief was adapted to produce a short 10-minute film featuring young people that have accessed the PETS service.

It is essential that young people's wellbeing is of paramount importance, and with this in mind Therapy Partners felt it was a duty of care to allow the young people wishing to share their stories enough recovery time to ensure that the production of the video did not cause distress or relapse.

This process of coproduction although being very effective in terms of deciding the content, provided the greatest challenges in terms of our commissioning deadlines. The video began filming in November 2016 and a first draft was received in January 2017 and after revisions were made the final video was signed off at the end of February 2017.

The video has proven to be instrumental in raising awareness and became a central part of the training program.

Even though the delayed production process was at times frustrating, given the feedback from all that have seen the video, it has been a worthwhile project.

Therapy Partners continues to use the video to raise awareness not only to families, young people, teachers and professionals but the wider public in general.

### *Patients Video Feedback*

***'E & I have watched this and both found it interesting and helpful. E did say that it would have been useful to her a year ago, if she had seen something like that as it may have made her realise sooner that limiting your food intake is not such a great idea. She said the reason she thinks it would help people is for the same reason that she enjoyed the Embrace film - it is real people talking about real life, not just a story you are reading. It was helpful to see young girls talking about how it actually affected them as people, not mum telling her what could happen (but might not!). From my point of view, it was nice to hear them talking about it frankly and openly but it didn't come across too "scary", in that it was also showing that there is hope and you can recover with the right help/frame of mind' – Mother of Young Person, North Kent***

## PETS ALIGNMENT WITH THE KENT LOCAL TRANSFORMATION PLAN FOR CHILDREN

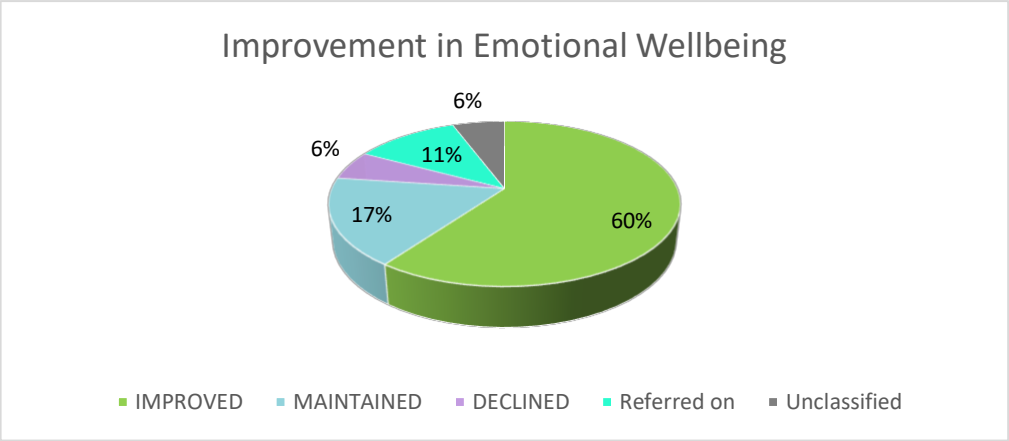
The Kent Local Transformation Plan for Children, Young People and Young Adults' Emotional Wellbeing and Mental Health defines three key areas for a whole system change over the next 5 years. These are: early help, access to support and a whole family approach.

The PETS programme met the outcomes in the following areas;

### *Early Help*

**'Children, young people and young adults have improved emotional resilience and where necessary receive early support to prevent problems getting worse.'**

A self-assessment questionnaire completed at the end of therapy to determine service satisfaction and overall wellbeing showed that 60% of those who received early intervention and support felt a significant improvement in their emotional wellbeing.




### *Access*

**'Children, young people and young adults who need additional help receive timely, accessible and effective support.'**

During the PETS pilot, 100% of accepted referrals were contacted and/or seen face-to-face within a week of referral, at a venue convenient to them. The EDE-Q results demonstrate the CBTE individual therapy had a high success rate, with 57% of young people having improved scores; 25% of these reducing to what is considered the community norms on global scoring scale.

### *Whole Family Approaches*

**'Children, young people and young adults receive support that recognises and strengthens their wider family relationships.'**

100% family members were engaged where available. Feedback and case studies demonstrate inclusion of family members and that they had improved communication skills and could identify strengths and weaknesses within their own family system.

### *ACHIEVEMENT OF KEY TARGET AIMS*

Alongside the above outcomes within the three main areas of delivery; individual therapy, peer support groups and awareness training, Therapy Partners have achieved the following key target aims set out by the PETS specification and evidenced in this report;

- *Evidence-based therapy (CBT-E) to children and young people with an eating disorder in the community to aid recovery and build resilience and to help them live their lives to the full.*
- *Carers with the skills and knowledge needed to support and encourage Children and Young People (CYP) and help prevent barriers to recovery.*
- *Enhanced emotional Intelligence in the client families whilst improving social and human factors.*
- *Reduced demand on secondary care Children's & Adolescent Mental Health services (CAMHS).*
- *Increased awareness amongst school staff and equip them with the knowledge to support them to identify students who may have an eating disorder.*
- *Support for aiding recovery and prevent relapse.*
- *Person-centred, collaborative and client-led experiences.*
- *A single point of access.*
- *Measurable outcomes.*
- *A reduced stigma of mental illness.*
- *Response to the individual needs of the young person.*
- *Easy to access "right service at the right time."*
- *An evidenced-based treatment protocol.*
- *Accessibility in the community or at clients' home at a time to suit client's lifestyle which has included evenings and weekends sessions and telephone and online support.*
- *An appropriate balance of group and individual treatment based on client's needs.*
- *Peer Mentoring Support from Young People who have lived Experience of Eating Disorders who have recovered.*
- *Engagement with Families, Carers and Significant others in the process of recovery whilst providing support.*
- *Links to help the clients maintain or develops links to on-going treatment and support services.*
- *Appropriate endings, signposting and follow up.*

## THERAPY PARTNERS FEEDBACK AND RECOMMENDATIONS

- *The level of presenting clinical need far exceeded expectations for a 20-session treatment in most cases.*
- *The majority of older clients presented with entrenched and enduring eating disorders, often with complex co-morbidities.*
- *Family dynamics and support networks were almost always an issue.*
- *There is clear need for early intervention with support required for younger patients from 10 years upwards.*
- *Many young people present with a BMI lower than 16.*
- *Those with enduring eating disorders represent a challenge to make lasting change to the eating disorder mind-set and would benefit from the 40-week broad version of treatment (Fairburn, 2008).*
- *Significantly underweight patients are also likely to require a longer treatment of 40 weeks due to the protracted time it takes to increase weight into the healthy range at 500 calories per day.*
- *It is evident that treatment will be more effective if the eating disorder is not established and thereby lends itself to early intervention.*
- *Early accurate assessment of the young person's engagement to treatment is critical to successful outcomes.*
- *The effect of social media, the media and movements like 'clean eating' threaten to increase the numbers of young people presenting with eating problems in the future and their attendant mental health co-morbidities.*
- *A stepped down transitional support mechanism would be recommended post treatment.*

### *CAVEAT – BARRIERS & RESISTANCE TO SERVICE DELIVERY*

Initially concerns were raised as to the efficacy of our treatment; these concerns were raised in writing by CAMHS and were responded to. The copy of the letter is attached in appendix B, supported with further dialogue alongside several meetings being set up with CAMHS at different locations throughout Kent. Referral pathways and a description of our clinical outcomes assessment governance criteria were discussed which facilitated a collaborative relationship with CAMHS which provided ongoing referrals with regular dialogue taking place since the inception of the pilot.

## PETS LEGACY

This pilot was the inspiration for launching the charity, Rewrite Your Story, in order to continue Therapy Partner's work with the local Kent community, especially its children and young people, offering support, guidance and therapy.

After achieving positive outcomes with the PETS project, receiving many referrals and treating patients quickly, reaching over 2,500 young people through school assemblies and presentations and providing eating disorder awareness training for professionals, it is evident there is high demand for these services.

Our aim is to support children and young people suffering from eating disorders, and those close to them including parents, friends and teachers. Our work has a special focus on early intervention and quick referral to treatment time.

Through our charitable work, we intend to spread an important message of positivity, good health and wellbeing offering help and support across the South East.

www.rewriteyourstory.org.uk
www.therapypartners.co.uk

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**EVIDENCE BASE FOR FAMILY THERAPY support**

The evidence based Systemic competences have been based on the following:

• The competence framework developed by Roth, Calder and Pilling (2011), and published at: http://www.ucl.ac.uk/clinicalpsychology/CORE/competence_frameworks.htm
• The "Blue Book" training standards of the Association for family therapy
• Leeds Manual
• Tavistock Clinic Childhood Depression Manual
• Diamond Manual for Attachment Based Family Therapy for Depressed Adolescents
• SHIFT (Self Harm Intervention Family Therapy) manual
• FFT Manual
• Maudsley Child and Adolescents Eating Disorders Service model and Family Therapy training manual

***Note: All names have been changed to protect patient confidentiality.***

## APPENDIX A: Letter to Local Authority for patient support

20 January 2017

Dear Sir/Madam,

**Re: NZ638856D**

I am writing to you to explain our involvement with Amy and her family. Therapy Partners are commissioned by the CCG's in Kent to deliver Eating Disorder therapy and to provide family support. I first met Amy last year after she had contacted Therapy Partners to request support for herself and her daughter Tia.

Tia has Bulimia a more severe case of eating disorder. We are currently offering Amy support to help her understand how to support Tia through her recovery.

It was quickly identified that Amy was in financial difficulty, as she was caring for Tia, but not receiving financial help with this. Tia was unemployed and not in receipt of any benefits and Amy was supporting Tia on her own. Tia's condition means she eats a vast quantity of food, which she then throws up. This is a significant, serious and dangerous, mental health condition and not an issue around diet or self-control. Amy's food bills are double, and if not triple, what the average person on her income would spend as every time Tia eats all the food in the house Amy has to replace it in order to provide food to her other two daughters, and so the cycle starts again.

Amy is trying all types of methods to help herself and her family, even receiving counselling herself, and she wants XXXX to get better. Amy is proactively trying to resolve her issues, and this includes trying to find other jobs with a higher income. All of the issues within the family have had a significant impact on Amy and her own mental health and to some extent she has had no option but to get into debt due to the lack of financial help she has received. The family would be destroyed if they now lost their home and the devastating impact this would have on Tia and Amy cannot be conveyed in a simple letter.

I am more than happy to discuss this further and to assist in any way I can. We do provide free training to organisations on how to support someone with an eating disorder, and perhaps this may be useful.

If you have any further queries then please do not hesitate to contact us.

Yours faithfully,

XXXXX Therapy Partners Limited.

## Appendix B: Letter to CCG in response to CAHMS Concerns

Attn.XXXXXXX
North Kent CCG.
Dear XXXXXXXX

Thank you for your email of the 25th July and please accept my apologies for the delay in responding as I was away attending CPD.

As a responsive and reflective organisation we always welcome feedback from peers and third parties therefore I would like to alleviate your concerns in writing to confirm that PETS Pilot Project is a NICE compliant service. As a professional organisation offering therapeutic support all that we do is based on sound research underpinned by using modalities of therapy that are best practice and approved by NICE as such I have included current research to underpin responses to SPFT, s concerns. Moreover, we would like to work alongside SPFT (Sussex Partnership Foundation Trust) and offer SPFT a collaborative approach to partnership working to ensure we can offer the children and Young People of Kent the best possible outcomes.

I would like to put it on record that we have engaged with Sussex Partnership Foundation Trust. My colleague DW has met with colleagues from SPFT namely Paul Haith and he has also had conversations with WG with a view to meeting up when he returns from annual leave.

Firstly, by way of clarity we disagree with your colleagues at Sussex Partnership Foundation Trust (SPFT) interpretations regarding CBTE (The email lists this as CBTe which is computerised Cognitive Behaviour Therapy for anxiety and Depression).

In response to the first concern raised that CBTE "Is not a first line treatment for young people, the National Institute for Health and Care Excellence (NICE) guideline for Eating Disorders in over 8s Management CG9 Published January 2004 treatments may include analytical therapy (CAT), cognitive behaviour therapy (CBT) and interpersonal psychotherapy (IPT). Focus of treatment should be on weight gain, healthy eating, and reducing other symptoms related to eating disorders. Conversely if SPFT argue it is not a first line treatment approach I would question as to why then are they using it?

In terms of operating within Multi-Disciplinary teams CBTE, in outpatient settings, has been designed for delivery by a single therapist (Dalle Grave, 2013 p.44) as this avoids the common problems observed in multidisciplinary treatment, in which patients partition their problems and discuss specific issues with specific therapists. It could be said that in this scenario there is a risk that no one is in a position to appraise the full clinical picture and patients may therefore receive conflicting and confusing device about how to address the same problem (Fairburn, Cooper, & Shafran, 2008 p.30).

A further potential of delivery of treatment by a single therapist is that is also more practical and easier to disseminate than those involving multiple therapists and can be accessed locally in the community. Also given staffing/ recruitment issues with SPFT it's more commercially viable and offers costs savings to commissioners.

One caveat to this would be for patients with high clinical severity who require multiple and complex professional skills and inevitably a multidisciplinary approach.

Eating Disorders are essentially "Cognitive Disorders" and share a core Psychopathology that is cognitive in nature. CBT by its very nature is designed to produce cognitive change. CBTE is the leading evidence-based treatment for adults with an eating disorder and is a specific form of cognitive behaviour therapy CBT-E.

CBTE is a one-to-one treatment that focuses on the characteristic disturbances in eating habits and attitudes to shape and weight. It was developed by Fairburn, Cooper and Shafran (2003) as a treatment for bulimia nervosa and in this form it has been the subject of numerous clinical trials. It

was the first psychological treatment (for any mental disorder) to be endorsed by the National Institute for Health and Care Excellence (NICE).

Enhanced CBT (CBT-E), has been tested across the full range of eating disorders in studies emanating from the UK, Australia, Denmark, Italy and the USA.

Modification of treatment in early 2000 makes it suitable for all forms of eating disorder (Fairburn, Cooper and Shafran, 2003) as it's a "trans-diagnostic" treatment, treating the eating disorder psychopathology rather than an eating disorder diagnosis.

Currently as matters stand, current research findings may be summarised as follows:

CBT-E has been shown to be suitable for all forms of eating disorder encountered in adults (Fairburn et al, 2009; Fairburn et al, 2013). This is not true of any other treatment.

CBT-E has also been shown to be effective in the treatment of younger patients (Dalle Grave et al, 2013). It is therefore a potential alternative to the leading evidence-based treatment for this age group, family-based therapy

CBT-E may be used in inpatient and day-patient settings

Focusing on the studies in which CBT-E was well-delivered, CBT-E has been shown to be more effective than two other widely used treatments

It has been found to be more effective than the leading alternative psychological treatment for adults, interpersonal psychotherapy or IPT (unpublished results)

It has been found to be more effective than 100 sessions of psychoanalytic psychotherapy delivered over two years (Poulsen et al, 2014)

I believe this answers the initial concerns raised by Dr A M M MD from SPFT around concerns 1, 2, 3. In terms of points 4 and 5 around delay of accessing services for the most appropriate treatment our intentions with this pilot was to compliment SPFTs services and offer early interventions which have positive impacts on patient outcomes and help manage their waiting lists and get people into treatment early thus avoiding further complications and health concerns in later life.

In terms of point 5 "delaying evidence based treatment" CBTE is an evidenced based treatment and at all times when working with patients their mental and physical health will be closely monitored. We as an organisation have a strong duty of care to our patients. The Pilot aims to work with people who are not significantly underweight, and not of a clinical severity to need access to secondary services. Again in relation to point 5 I would say that CBTE is an evidenced based treatment that aims to address the eating disorder psychopathology rather than the disorder as diagnosed by DSM. The treatment is primarily concerned with the process that act to maintain the psychopathology with cognitive process being viewed as of central importance.

Finally, we would welcome further dialogue with the CCG with regard to potential solutions suggested to use the therapeutic time for young people with binge eating disorder for who there is no therapeutic provision currently as outlined by Dr A M.M MD.in her email.

I attach the guidance notes for CBTE and links to The Centre for Research for Eating Disorders at Oxford CREDO. http://www.credo-oxford.com/

Yours sincerely

Alan Heyes, on behalf of Therapy Partners Ltd.

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## Appendix C: Case Studies

### *Case study 1*

Mum is a single parent to 3 children and she grew up in care. The father of the two of the children is currently awaiting trial for sex offences for the child he did not father, this is the child with the ED – bulimia. Mum changed from a good employment role to a part time role on minimum wage, as she did not feel capable of anything else. Mum struggles financially as she spends over £200 a week on food. The daughter with an ED had to give up uni as she got into significant debt as she spent all her money on fees. She is now unemployed due to her ED leaving her unable to work. Mums parenting style maintains the ED and the two younger children are exhibiting signs of an ED and/or other behavioral and mental health issues.

Support provided to date: Mum - provided with counselling (even though this was outside our remit but such was her need). Support given in parenting methods for someone with an ED and family referred to DWP as not receiving full range of benefits. Mum attended training. Daughter – receiving counselling, attending peer groups and training. Siblings – referred to carers' organisation for their own support. Family as a whole – family therapy

NB. It took a lot of time to gain trust and to start to work with this family. Mum states she was at breaking point and had developed serious mental health issues. Mum states that without support and the ED being treated as whole – with everyone in the family being supported, she feared she could not look after her children anymore. Mum has since gone on to get a new job at a higher wage. We supported this Family and were successful in preventing eviction from their Home refer to letter in Appendix A

### *Case Study 2*

Katie is a young lady who was referred to Therapy Partners by her mother and her school pastoral carer following concerns that Katie had collapsed at school following a PE class.

Katie's mum had noticed over the past 6 months that she had started to be picky with her food at the dinner table and started refusing to eat certain foods. She had also started to intensively exercise in her room and weigh herself every day.

School were also concerned they had noticed that Katie did not appear to be eating at school and was throwing her sandwiches in the bin. This came to a head when she had collapsed at school after a PE lesson and refused to eat chocolate when offered.

Katie was assessed at home with her mother present and it started to become clear that since an issue of bullying 7 months previous to the date of assessment where she had been called fat by one of the boys at school she had started to become obsessed with her body image and weight.

She was negatively evaluating herself, restricting her food and over exercising as a way to try to make herself feel better. However although she was losing weight her self-image and confidence were not improving therefore the whole cycle continued.

Katie was now stuck in a cycle where she was restricting food and over exercising to make herself feel better but this was having the opposite effect and she was feeling worse

about herself and her mood was dropping substantially. She had also started to isolate herself from her friends and family and this had a further detrimental effect on her mood.

Her family were also struggling and her mum felt that she did not know how to manage the situation and help Katie feel better but she admitted that she felt completely out of control and helpless.

It was therefore agreed with Katie and her family that she would commit to 20 sessions of CBT-E treatment with Therapy Partners to try to help her to break the cycle of her eating disorder and move forward in her life.

Following 14 sessions of CBT-E treatment Katie is now back on track with her life. She no longer restricts her food and is eating regularly with her family and with friends in school. She advised me that although she does have days when she worries about the way she looks she no longer wants to restrict her food intake as she is aware that this is detrimental to her wellbeing.

She has learnt the importance of regular eating to the wellbeing of her mind and body and has developed an understanding as to how outside influences had impacted on her self-confidence. She has also gained a greater understanding of how she was using worry and negative self-evaluation as a way of coping with perceived criticism.

Through her treatment Katie has been able to learn more helpful strategies to help her manage difficulties that she experiences both at home and at school and she advised me that she has gained a lot of self-confidence throughout the program.

Katie's family have also benefited from the program in that her mum advised me that she is no longer "pulling her hair out" with Katie. She now has a greater understanding of how to manage Katie's difficulties and Katie and her mum have grown closer through the whole process of treatment. Katie's mum also fed back that it was good for her to be involved in the treatment as she felt enabled and less helpless throughout the whole process.

Throughout the treatment Katie gained 5kgs and her weight has remained stable for the last 6 weeks. She is due to be followed up in 2 weeks.

FAMILY INTERVENTION - Katie's mum Anne said that she was 'tearing her hair out' and was frustrated by Katie's behaviour as she found this difficult to deal with, she found that her relationship with Katie was being affected by this.

Anne was offered psycho-education by way of attending a workshop on Eating disorders which is based on the New Maudsley Method of caring for a loved one, where she learned to identify some helpful strategies for communicating with Katie.

Anne and Katie had a joint appointment to assess the difficulties from both perspective and to jointly agree the treatment plan. As Katie was seen at school, it was agreed that Anne would call the therapist after each session for an update (with Katie's permission). This worked well as Anne felt like an active participant in the treatment and was able to work alongside Katie at mealtimes. Anne attended further review meetings and was able to access telephone support with a therapist whenever she needed to. Anne reported that this was very helpful as she felt included and could work through her feelings of guilt and helplessness, and that her relationship with her daughter had improved significantly.

### *Case Study 3*

14yr old underweight female (mid-term) Current weight 42 kilos - BMI 6th percentile. Height: 160 cms

Mum was keen to get S seen as soon as possible and rang repeatedly to hurry the process. The initial assessment mum explained that she was already experienced in anorexia nervosa as S's elder sister has been hospitalised for the same condition in the previous year so was familiar with the effects and was aware that S restricting food and social withdrawal was escalating very rapidly. Mum had attended the parenting course which had empowered her with knowledge but understood that this would need to be a journey for S to take control of. When completing the eating questionnaire S seemed to score surprisingly low and did not believe that she suffered with an eating disorder but attended as mum wanted her to. S spoke so quietly I could barely hear her talk and she found it difficult to lift her head to talk to me but confirmed that she self-harmed too but tried not too as it upset her parents and she didn't like to let them down. S explained that she had been bullied at her previous school and had just recently moved to a new school. S wanted to be home-schooled as she still felt very unsafe around young people but her parents do not understand her or listen to her. S had never weighed herself but it was very clear to see that she was very thin. On the onset S considered herself to be 15% committed to treatment.

S arrived with her Real Time Monitoring forms with very little food on them and although the patient still felt that she did not have disordered eating she could see that it was probably not enough food for a person to survive on long term. We looked at the comments on the forms and had to break down her thoughts around food and what she might be thinking when consuming or avoiding. S began to flow with information that she had been very unaware of which surprised her. We looked at becoming an expert on herself and seeing what she could discover. S was onboard with being an expert and it didn't take her long to start uncovering negative thinking around food and how that affected her eating habits. After introducing regular eating and planning I noticed that S wasn't doing this so we explored. It seemed that living in a family with so many meant there was little food left soon after shopping day which was done once a week so S felt unable to plan and felt that she could not raise this as she knew mum had little money to buy food and didn't want to put any more pressure on the family. S worried about mum as she suffers with depression spending days in bed at times. Exploring with S the family situation and the need to have her basic needs met seemed alien to her, recognizing S's lack of understanding I could see that this could be a family issue of not having their basic needs met. Discussing my concerns with S about the lack of food being available to her limited us to exploring issues around food as it seemed she believes she doesn't eat because of lack of food. We discussed talking this over with mum and looking at mums needs too. Putting into place a plan with mum to provide food for the whole week to support S meant that she was then able to identify that there was much more to the disordered eating than she had thought as she continued to not eat very much. S realised that she felt others deserved the food more than her and that in not eating she was 'being kind' to the rest of the family, she also realised that her sister being hospitalised meant she was the focus of her parent's attention which is something she craved. Identifying the reasons to maintain this way of eating helped S accept there was more to this than she had originally thought and she confirmed to that she thought she did have an eating disorder. We looked at psycho education around lack of eating and raising her awareness has informed her and brought her attention to how her body is coping with the lack of food, this has encouraged her to start to look at commitment to change. Now able to identify the thinking around eating we looked at ways of testing out her theory that her parents do not understand her, listen or take in what she tells them. Bringing mum and dad into the waiting room and asking them to fill in the pockets on a picture of an empty rucksack of the 'things that S is carrying around with her that weigh her down' and then asking them to come into the session and explain all of the pockets one

by one to S. S was very taken aback to how full the bag was and how much they really had heard. S was able to recognise during this that she was important and they do hear her. The next session we were able to look at a 55% commitment to change, create a 'pros and con table' for staying as she is and then a 'reasons to change' table. We then looked at what column was most appealing which was the reason for change. S then changed her commitment to 65% and has decided to take the steps towards change. S is investigating different drinks which will support her weight gain and we will be doing a taste test in the next session.

Giving S space to explore eating in an autonomous inquisitive way and looking at different visual scaling techniques she has moved from having very little self-awareness to aware and now able to make decisions towards change in the following weeks.

Discussing with mum S's needs and how we can meet them in the future and how mum currently meets her own need it became apparent that as a family, life has been very chaotic for quite a while now. Mum was involved in a very traumatic event resulting in her being in a coma for 3 weeks 2 year previous, leaving her with depression and long periods of being unable to get out of bed. It appeared that for S to get her needs met mum would have to too. Identifying the family's needs being an integral part of S's recovery Mum is now receiving counselling too to help her identify and met her needs as well as S's.

### *Nutritionist Case Study 1*

Young Person. DGS area.

This patient is an 18 years old female with a history of bulimia for 3 years, she did not eat regularly and had difficulty with social eating. Additional concerns raised by her mother was that she is not getting adequate nutrition, and might not be ready to go back to school in September.

Throughout the patient's illness, the family felt that they would benefit from someone working with her to create a healthy eating plan tailored to her needs and likes.

It was important for the patient to be able to maintain energy levels and confidence with regular eating as they will be going into the final year of A-Levels, studying dance and personal training which are both high physically and mentally intense.

It was apparent that the family are aware of what constitutes a healthy diet with the patient's mother providing healthy evening meals daily.

I prepared nutritional information and explained in detail the benefits of regular eating and avoiding negative eating behaviours to be able to have adequate nutritional intake and energy to succeed at school and socially. We discussed the principal of basal metabolic rate with a high activity level and her personal daily requirements. The patient responded well to positive advice and guidance.

The patient became happy to look at the menu or options available to her prior to eating out which reduced the level of anxiety felt.

A spreadsheet was developed with a tailored meal plan for active days and non-active days with timings of food and drinks and examples of meals to guide and motivate the patient to eat regularly. Therapy Partners Nutrition Pack with nutritional guidelines, recipes, meal plans and other useful information was also provided. The importance of regular eating and drinking was emphasized to maintain energy levels and concentration in school.

The patient developed a better understanding of nutrition and healthy eating behaviours. We discussed how eating out with friends, or enjoying less healthy foods on occasions, was not to be viewed as binge eating. I assisted the patient with blank food diaries to be able to manage her food and drink intake which she is using with the support of her mother.

Feedback from mum:

"We have found the programme and information given really helpful, <the nutritionist> seems to have found just the right approach for H and has given us just the right mix of information and understanding
H seems to be engaging with her and is certainly thinking about what and when she will eat in a more realistic way.
I think that this is certainly the most relevant help we have received so far and the first time I feel H is showing signs of positive involvement in her treatment".

### *Nutritionist Case Study 2*

This young person was referred after 6 individual session with one to one CBT-E therapy, after she reported better communication with her mother with whom she had a difficult relationship. She asked for specialist advice and was therefore referred to our nutritionist:

Young person's difficulties:

It had been a long time since she had eaten normally she was feeling at a loss to know what was good and bad, due to the many different rules she had in place, she felt that she didn't know what to eat and experienced a lot of stress around food choices and does not enjoy eating

She has been through periods of anorexia, bulimia, binge eating and laxative use. A plan and guidance would be really useful to follow, with guidance and talking through some of the rules.

She was encouraged to plan one or two days ahead depending on their work schedule and gym class/ team sports club. They were happy to try this so that the pressure is off when they come in and are tired, not in a positive mood which usually leads to binging on unhealthy food and negative emotions surrounding this. She was happy and reassured by this plan as due to shift pattern it was difficult to plan a whole week. I also emphasized that it is essential not to be too strict as building confidence and a creating a positive relationship with food is the main priority.

We discussed what kinds of meals the patient enjoyed and building interest in cooking again which is something they used to really enjoy. I was pleased to acknowledge that the food choices were generally really good and there was understanding of balance and eating to look after yourself (maintain energy to be able to reach goals

**Conclusion:**

The patient is now more confident around her food choices and planning ahead has definitely improved eating regularly. She is planning what she will eat in advance to avoid negative behaviours and encourage more structure and healthy eating habits.

She felt happy with the 'fresh start' and moving towards healthy eating behaviours. I was able to give the patient positive reassurance on the fantastic achievement she had made so far in moving forward with her goal of becoming healthy and going back to university in September which had been a cause for high anxiety for her.

On follow-up: She has since started a new job in London 3 days a week, is studying again and is doing really well. She has gained confidence in managing her eating and in having the confidence to pursue the career she wants.

## Appendix D: Service User Feedback

**"I am glad I am on the program as it is helping her. Initially I was sceptical about it as I wasn't sure if it would work. Regular eating has been a great help" – Service user**

**"It's a good service and I have improved. I like coming, it helps me to talk. I've stopped weighing myself as I know I will be weighed every week. I like that it went from two session a week to one and it helps so I can get used to ending the service" – Service user, 19 years**

**"I have learnt that weight and appearance aren't everything and to focus on other things. I value myself much more as a person now. I always thought that I was over-eating but reviewing the sheets has been very helpful, even though I found it awkward and embarrassing to start with" – Young person, Canterbury**

**"Not sure knowing what would happen to me in counselling, I now look back and feel an overwhelming sense of relief from lots of unspoken issues. Now I feel I have some space to acknowledge there is a me somewhere. I just have to recognize her and welcome her home"– Young Person, Folkestone**

**"My sleep has improved and so has my energy, I've started eating in public which was difficult before" – Young Person, Thanet**

**"I feel much better about myself now and I realise that I eat unhealthily. I know what to do about it now" – Young Person, Dartford**

**"I feel a lot better, and have not 'thrown up' for months, I don't want to and don't even think about it anymore even if I feel that I've eaten too much" – Young Person, Ashford**

## Appendix E: Parent Feedback

**"I would like to offer my feedback regarding the help that Maya and I have received from yourself over the past 7 months.**
**As you are aware, I became concerned with the way Maya seemed to be acting around food and body image. After a number of weeks I took her to our GP who advised that at the time she was just in the healthy BMI range and apart from a brief 5-minute conversation about the importance of eating that was as far as the GP interest went.**
**I considered for a week or so whether I should make Maya's school aware of what I believed could become a serious issue, they thankfully took me seriously and told me about the Pilot scheme that was happening, hence the involvement of yourself.**
**At the time of contacting you guys, Maya had just turned 13 and I think there was an initial concern that she may be too young for the scheme being offered. However, after a phone conversation it was agreed that the scheme may be of help to Maya this in my opinion was the best decision ever.**
**She has benefited greatly from having someone outside of the family/friends to talk to and to make her consider her thoughts in a different way. Over time she has understood that images you see in magazines/social media etc. are not always true images, and that things people say shouldn't impact the way you feel about yourself.**

**This has been a long hard journey but one that has been made easier by your support. As a parent I am sure I just sounded like I was continually nagging her to eat and as a teenager her view was different to mine. I am of no doubt that this program and outside support has given us a totally different experience and journey to one we could have taken if we had been left to our own battle as to whether it was important to be a particular weight or not!!**
**Whilst Maya may still have the odd day of rolling her eyes at me when I ask what she has eaten she is now saying she is hungry and is now snacking like I would expect any "healthy" teenager to be.**
**Maya would be more than happy to discuss how this program has impacted her if this would be helpful. Thanks again for all your support." - Mother of service user, Feb 2017**

**"It's really helping L, and she seems much happier…you have been great at keeping in touch with me" – Mother of service user**

**"I became concerned with the way Sophie seemed to be acting around food and body image. After a number of weeks, I took her to our GP who advised that at the time she was just in the healthy BMI range and apart from a brief 5-minute conversation about the importance of eating that was as far as the GP's interest went.**
**I considered for a week or so whether I should make the school aware of what I believed could become a serious issue, they thankfully took me seriously and told me about the Pilot scheme that was happening, hence the involvement of yourself.**
**Sophie had just turned 13 and I think there was an initial concern that she may be too young for the scheme being offered. However, after a phone conversation it was agreed that the scheme may be of help to Sophie - this in my opinion was the best decision ever.**
**She has benefited greatly from having someone outside of the family/friends to talk to and to make her consider her thoughts in a different way. Over time she has understood that images you see in magazines/social media etc. are not always true images, and that things people say shouldn't impact the way you feel about yourself.**
**This has been a long hard journey but one that has been made easier by your support. As a parent, I am sure I just sounded like I was continually nagging her to eat and as a teenager her view was different to mine. I am of no doubt that this program and outside support has given us a totally different experience and journey to one we could have taken if we had been left to our own battle as to whether it was important to be a particular weight or not!!**
**Thanks again for all your support." – Mother of Service user**

## Appendix F: Therapist & Nutritionist Feedback

**'I saw the patient again this morning and she said that regular eating has meant that she no longer has painful hunger pangs. Having food in her stomach gives her confidence and in class she engages more and is more attentive. She said when she was hungry, she would withdraw, only contribute when she had to, and generally felt negative. She finds the sensation of being satiated comforting.' – Therapist**

**'I spoke to her this evening for her post treatment review B said she is much better. She said she feels a lot better, has not 'thrown up' for months, doesn't want to and doesn't think about it. If she feels like she has eaten too much, she doesn't then want to 'throw up.'**
**She is going back to Uni in two weeks. She still has problems with not eating properly and still has problems with shopping for clothes. She re-engaged in The XX (Uni degree) which is brilliant! She is taking steps to look after herself by commuting to Uni and staying at home. This is because she knows she will likely not eat or cook if she lives away from home. Socially, she has re-engaged with her friends and enjoys it more than she used to. She used to be totally preoccupied with her body, feeling fat and consequently not eating or avoiding food.**
**Finally, she said the therapy 'definitely helped' her and described it as a 'delayed result.' For me, Inside, I felt great! So great to hear that she feels so much better. It just shows that a difference can be felt/noticed later and not always evident in data.' – Therapy Partners Therapist**

**"As nutritionist for Therapy Partners, I provide nutrition information, guidance and support for the team of therapists as well as personal support for patients where needed.**
**Support I have given so far includes information packs, diagrams and other useful tools, nutrition education sessions during monthly team meetings and 1:1 advice to several members of the team to support their patients in their journey to recovery. I have also had the opportunity to contribute towards the new 'Rewrite your story' website, assisting in the management of the teams social media and will be contributing towards materials for the new Therapy Partners website including nutrition blogs.**
**The feedback from the team so far has been positive, as concepts such as BMR, and information surrounding consequences and outcomes of poor nutrition have been made available.**
**I have had a direct referral for a patient that would like further nutrition guidance and support and will be connecting with them for an online nutrition coaching session centred on key pre-planned themes the patients would like to discuss"- Therapy Partners Nutritionist.**

## Appendix G: Current Service Provisions

Previous reports from the Royal College of Psychiatrists and more recent mapping studies and needs assessments of specialist service provision for eating disorders have shown a picture of at best patchy and at worst non-existent provision of specialist services in many parts of the UK and Ireland.

There is considerable variability in the treatments provided for young people with an eating disorder following essentially two main care pathways.

The first and most common is from primary care to a local CAMHS that will have varying levels of expertise in eating disorders and may have a variable mix of treatments available.

Because of the potentially life-threatening nature of Anorexia Nervosa and sometimes the delay in getting treatment, a significant proportion will be treated in hospital.

The National CAMHS Audit (2005) showed that around 35-40% of child and adolescent eating disorders cases are treated in hospital at some point and recent data suggest that with young children the proportion treated in hospital may be even higher (Nicholls et al 2011).

Although some admissions (e.g. those to paediatric wards) are brief, most admissions are long, with an average duration of stay of 18 weeks (Royal College of Psychiatry, 2012) with significant numbers of admissions lasting considerably longer.

Adolescents with eating disorders account for the largest number of admission to hospital of all mental health problems in the UK and the highest proportion of inpatient stays exceeding 90 days (Royal College of Psychiatry, 2012).

Residential treatment has relapse rates of 25-30% after the first admission and 50-75% for second or further admissions (Steinhausen et al 1993; Strober et al 1997; Lay et al 2002).

The second referral route is to a specialist outpatient Child and Adolescent Eating Disorders Service (CAEDS). These are dedicated multidisciplinary services covering a larger geographical area than a single CAMHS. Although these have been growing in number in recent years they are still relatively rare in the UK. The establishment of a specialist CAEDS has been reported to reduce rates of admission to hospital by as much as 60-80% (Berelowitz, 2004).