



Briefing report to Norfolk Health & Overview
Scrutiny Committee – 11th April 2019 –
Eating Disorders (ED)

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Eating Disorders Services – Norfolk & Waveney, all age groups & tiers

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1. Context

Eating disorders are a group of illnesses in which the sufferer experiences issues with body weight and shape, which disturbs their everyday diet and attitude towards food. Eating disorders (ED) are usually long-lasting and have serious implications, including risk of death, impaired health, psychiatric comorbidity and poor quality of life for the patient and those around them. The risk of early death in this population is among the highest of patients with psychiatric disorders, whether due to physical complications (e.g., multi-organ failure) or mental health issues (e.g., suicide). The weighted crude mortality rate is approximately 5.1 deaths per 1,000 person-years for anorexia, and 1.74 per 1,000 person years for bulimia¹.

Mainline therapies for eating disorders, outlined by the National Institute for Health & Care Excellence (NICE), are clearly set out and are predominately based on Cognitive Behavioural Therapy or Family Therapy approaches. Across Norfolk & Waveney the different services use different approaches proportionately and appropriately, following NICE guidance for the main part.

Knowledge of services across the East region identifies that a variety of inpatient and community eating disorders services face recruitment & retention challenges, with multi-faceted causes. The

¹ Arcelus, J., Mitchell, A. J., Wales, J. & Nielsen, S. 2011. Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. Arch Gen Psychiatry, 68, 724-31.

Strategic Clinical Network (SCN) for eating disorders in the Eastern Region recently identified that services in the area have experienced vacancy levels of 6% to 37% in the 12 months of 2018. Competition for experienced, qualified workforce in this area of specialism is high with other competing specialisms trying to attract this level of skilled practitioner and the potential for the death of the patient and the subsequent processes higher in this area of work than in other areas of psychiatry

2. Statutory Services

2.1 Providers & background

Adult Eating Disorder Services (18 years +):

In **Central² and West Norfolk** these are commissioned from Cambridge & Peterborough Foundation NHS Trust (CPFT) and the Norfolk Community Eating Disorders Service (NCEDS). The coordinating commissioner for this service is South Norfolk CCG. These services are based from The Springs site in Sprowston, with satellite clinic offered in Kings Lynn. South Norfolk CCG are the coordinating commissioner for this service.

The Adult ED service for **Great Yarmouth & Waveney** (GYW) area is commissioned from Norfolk & Suffolk Foundation Trust (NSFT) through Great Yarmouth & Waveney CCG. This service is based at Northgate Hospital, Great Yarmouth.

Children's & Young Peoples ED (CYP-ED) services:

These services are commissioned from NSFT across Norfolk & Waveney, with South Norfolk the coordinating commissioner for Norfolk CCG's. These services are based at The Julian Hospital site (Central team), Northgate site (GYW team) and Thurlow House (West team).

Central & West Norfolk CYP-ED services are delivered to population ages 0-18years, GYW CYP-ED services are delivered to population ages 0-25years. This leads to GYW providing an all-age service and the Central & West system providing a CAMHS and adult offer with clear transition pathways as someone approaches 18 years of age.

CYP-ED services have a higher level of involvement with prevention and early intervention, consultation, liaison and education, and offer an assertive outreach approach where needed.

The Children's & Young Peoples ED (CYP-ED) service across Norfolk received a significant increase in funding through the Local Transformation Plan (LTP) in 2015, this was via national direction. All 5 Norfolk & Waveney CCGs agreed to align and pool their joint planning capacity and the anticipated new funding allocations in line with the intentions of both Future in Mind and NHS England's guidance regarding LTPs, producing a single LTP. In doing so, they work with a range of partner organisations from the statutory and voluntary sector, under the auspices of Norfolk's long established CAMHS Strategic Partnership.

At this time (2015), it was also recognised that at the time NSFT reported a 25% year on year increase in referrals to the CYP-ED service, both in numbers and complexity of morbidity, and they were no longer able to safely accept and treat this level of demand. As a result of the Future in Mind, LTP recommendations, significantly increased demand on services and new access targets,

² 'Central' includes North Norfolk, South Norfolk & Norwich CCG's

a very significant increase in the CYP-ED staffing was agreed and funded, in order to be able to provide safer and more effective delivery of ED services to CYP. This needs to be considered alongside the context, as outlined, of risk of death being higher in this patient group. These factors were all being seen nationally and replicated at a local level.

2.2 Staffing

Adult Eating Disorder Services (Central & West Norfolk) Norfolk Community Eating Disorder Services (NCEDS)

EDS team includes psychology and psychiatry staff, Cognitive Behavioural Therapy (CBT)/ED specialist therapists, psychology assistants, admin and team management. The staffing complement of the service is based on best practice guidelines nationally from NICE plus a local needs assessment conducted by UEA in 2012. The service is deliberately psychologically therapeutically modelled in accord with NICE guidelines

NCEDS is has experienced significant difficulties in recruiting CBT/ED specialist therapists for the past 12 months, which has had a dramatic impact on the ability of the service to meet demand and Key Performance Indicators. Papers outlining the position of the service were presented to the Joint Strategic Commissioning Committee in Autumn 2018

In November 2018 Cambridge and Peterborough NHS Foundation Trust took the action to raise the threshold for accepting referrals, such that it currently can only accept new referrals for those individuals triaged as having a severe ED or in need of priority treatment pathways. [*Please see later section within 'service performance' for further information on this issue.] They undertook this action for on the grounds of patient safety as a high number of patients were waiting considerable periods of time between the assessment process and starting active treatment.

Exploration of staff / skill mix is being reviewed to resolve current staffing challenges. The NCEDS team totals 12.1 Whole Time Equivalent (WTE) staffing, of which 2.4WTE are administrative staff and 9.7 WTE clinical staff. Vacancy levels have been around 3.3WTE for a significant period of 2018 and into 2019, all of which are clinical therapeutic staffing roles.

Recruitment campaigns have been undertaken four times without success and Agency and Locum markets are also short of this area of specialism. The Provider and the Commissioners have been working in partnership to implement new recruitment approaches and new modern techniques to work towards invigorating the staffing establishment, providing other means of service delivery with the aim to re-establish the original criteria for access to the service

The fifth recruitment campaign during January to March 2019 has been successful and resulted in the offer of appointments to the newly created roles of Clinical Nurse Specialist and Speciality Doctor. Once all recruited to positions are in post – pending employment checks and notice periods, anticipated to be by the end of May 2019 - the team will be close to full staffing capacity, dependent on no further changes to the staffing position. The cautionary caveat being that this staffing position is fluid and can change.

Adult Eating Disorder Services (Great Yarmouth and Waveney) – Norfolk and Suffolk NHS Foundation Trust

The Adult Eating Disorder Service covering the Great Yarmouth and Waveney area is commissioned from Norfolk and Suffolk NHS Foundation Trust. The team comprises a speciality

doctor, therapy and nursing staff, admin and support staff. The WTE in this GYW team, specifically allocated for the adult provision, equates to 4.5WTE. The model of service delivery in place is a more eclectic model than in the Central and West Norfolk area.

Children And Young Peoples Eating Disorder Service (Norfolk and Waveney) - Norfolk and Suffolk NHS Foundation Trust

NSFT team comprises Consultant psychiatry, associate specialist, clinical psychology, systemic family psychotherapy, CBT therapy, assistant psychology, clinical nurse specialist, senior nurses, assistant practitioner, specialist eating disorder support worker, social worker, occupational therapy, admin, specialist dietician, and community team manager. The CYP-ED team establishment totals 29.9 WTE staff.

From January 2018, for 6-9 months, the CAMHS ED service in the Central Norfolk team operated with staffing establishment and vacancies significantly below establishment, due to challenges with recruitment and retention. This had a knock on impact on service delivery at that time (see CYP-ED Service Performance section).

2.3 Service Performance

Adult Eating Disorder Services (Central & West Norfolk) - Norfolk Community Eating Disorder Services (NCEDS)

NCEDS provides treatment to people with an Eating Disorder of moderate to severe severity who require treatment for weight restoration or stabilisation, or management of abnormal weight control mechanisms. It provides treatment to people with the following diagnoses:

- Anorexia nervosa;
- Bulimia Nervosa;
- Eating Disorders not otherwise specified (EDNOS);
- Binge Eating Disorder.

NCEDS has locally determined Access & Waiting Time Standards contracted as follows:

- 100% of urgent assessments taking place within 4 days. For the 12 months to June 2018 this was met at 100%.
- 90% of routine assessments taking place within 28 days. For the 12 months to June 2018 73.8% of routine assessments were delivered within this Key Performance Indicator.
- Referral levels during this same 12 month timeframe totalled 133 accepted referrals. Since 2011/12 NCEDS have seen a 17% increase in the numbers of referrals received.

NCEDS provision of services to those people with moderate to severe Eating Disorder is determined using the following criteria, aligned to the Diagnostic Statistical Manual (DSM) of Mental Disorders diagnosis criteria, and outlined in table 1.

Table 1 – Adult NCEDS distinction for urgent and routine		
	Anorexia Nervosa	Bulimia Nervosa
Severe eating disorder	BMI<15kg/m2 Rapid weight loss Evidence of system failure	Daily purging with significant electrolyte imbalance. Co-morbidity, e.g. diabetes

Moderate eating disorder	BMI 15-17kg/m2 No evidence of system failure	Regular & frequent (>2 per week) binge eating & purging but no significant electrolyte imbalance Some medical consequences, e.g. chest pains, dizziness
Mild eating disorder	BMI>17kg/m2 No additional co-morbidity	Sub-diagnostic frequency of bingeing and vomiting purging No significant medical complications

As of the end of February 2019, NCEDS waiting list & times is as follows:

- Waiting list:
 - Awaiting assessment: 27, these are routine referrals accepted before the threshold was raised. For 2 patients who were referred back to primary care as a result of the temporarily raised threshold, GP's made contact about escalating concerns re patients' deterioration, for which NCEDS then provided a rapid assessment and first stage of treatment to stabilise the patient's condition. NCEDS were able to respond rapidly because of the managed referral process that has been put in place with the raising of the thresholds.
 - Awaiting treatment: 41 – all of these people have received the evidence-based 'Keeping Myself Safe' first stage intervention, all of those awaiting treatment are of either routine (27 people) or priority (14 people) need - none of these people are classed as urgent. Treatment is expedited where clinical risks rise.
- Average waiting time: 42 – 52 weeks from triage to 1:1 treatment. This is significantly impacted by the current recruitment challenges and 'honouring' the routine referrals accepted before the acceptance threshold was raised. The waiting time for treatment of those people classified as both priority or urgent will be significantly lower, and there is infrequently anybody waiting for treatment who is classified as urgent.
- The following demonstrates this, by outlining the time from referral to assessment for each category of patient:
 - Average waiting time for those newly referred (since the revised thresholds were implemented) and classified as
 - Priority: is 14.5 days
 - Urgent: is 2.25 days
 - Average waiting time for those on the routine waiting list which has been 'honoured' from before the temporary raising of the access criteria: 91.8 days

Temporary restriction of the Norfolk Community Eating Disorders Service

NCEDS notified the Commissioners of the Adult Eating Disorder Services (for Central & West Norfolk) Norfolk Community Eating Disorder Services (NCEDS), South Norfolk CCG in the Spring of 2018 about initial difficulties in staff recruitment and retention. This was raised as part of the regular meetings between the provider and the commissioner to monitor performance and any difficulties.

During Summer 2018 the situation was notified to Commissioners that the staffing situation was not resolving, although all normal processes to address were being taken. Clinical concern was being

raised about patients having to wait longer periods between triage, assessment and commencement of treatment stages and this situation becoming unviable and unsafe.

Due to the escalation of concern papers were taken to the Joint Strategic Commissioning Committee in the Autumn appraising them of the situation and requesting consideration of the need to raise the service threshold because of clinical safety concerns.

In November 2018 Cambridge and Peterborough NHS Foundation Trust informed the Commissioner that they had had to invoke the criteria threshold shift because of patient safety concerns. The Provider and Commissioner ensured that the detailed pathways and rationale for the change was sent out immediately to all parties.

An essential part of the care pathway for patients is the Medical Monitoring function that is undertaken by Primary Care, either via the Locally Commissioned Service mechanism or by Primary Care undertaking this as a part of their core duties. Hence there was an immediate need to keep colleagues in Primary Care, the main referral route, informed of the situation and what the temporary care pathway would entail.

Actions to mitigate:

CEDS service took the action to agree communications for stakeholders and affected patients. These include the information on support still available to them, including:

- Access to the evidenced first line psychological treatment ‘Keeping Myself Safe’ podcast and online workbook and resources
- Self-help resources widely available, including books on prescription
- BEAT (the national Eating Disorders charity) which provides helplines / moderated online forums for those affected by eating disorders
- Routes for re-assessment by NCEDS to accessing treatment

To address the concerns of providers (including acute and primary care), commissioners, service users, and other stakeholders, we have worked consistently and collaboratively to minimise the disruption and risk to all. The actions taken or explored to date include those in table 2:

Table 2 - Mitigating actions taken to address the disruption and risk associated with the temporarily raised threshold for NCEDS.
<p>Actions implemented</p> <p>- Discussions with the LMC and clinicians has led to NCEDS incorporating the following into their current service with its raised criteria:</p> <ul style="list-style-type: none"> • NCEDS will have a clinician on duty during daytime hours (09:00-17:00) Monday – Friday to be contacted to address Primary Care concerns or queries about: the current triage process and discussion of particular cases which have been triaged; concerns or queries about the escalation &/or re-referral of patients whose condition may have deteriorated in the community; Concerns or queries about patients who have been accepted into the NCEDS service. • Where a patient does not meet the raised criteria at the triage stage, NCEDS will provide bespoke advice for referrers regarding ongoing patient management. This is based on the referral information provided.
<p>Actions underway</p> <p>- Exploration of the opportunities to utilise existing partner organisations / services to support service delivery:</p>

- Eating Matters are developing a business case to offer Specialist Supportive Clinical Management – a non-CBT treatment approach for people with BMI >15. This has been positively received by commissioners who are working to implement this service as soon as practicably possible with available training and resources.
- NCEDS are leading on exploring the opportunity to provide on-line ‘remote’ CBT treatment for people with BN & BED (appropriateness for this treatment is determined along diagnostic lines, but is not for those with BMI <17.5). A meeting held on 4th March 2019 proved positive and the provider, HEALIOS, and CPFT are currently developing the CBT offer which is currently scheduled to be finalised by April of 2019.
- Newmarket House, the Norwich based specialist inpatient unit for people with eating disorders, are currently working up a business case to deliver an intensive community treatment offer for people moving out of inpatient care. This has the scope to improve flow to inpatient care – allowing NCEDS to transfer people in a more appropriate timeframe, reduce the pressure on NCEDS to respond to priority referrals and provide a more effective stepped care approach for this population.
- NSFT central CAMHS ED service are developing a proposal for delaying transfer of care to NCEDS for those people approaching the transition of care point determined by their reaching the age of 18 years, where clinically appropriate. This could relieve demand on NCEDS to respond to these priority referrals, but impact on the service’s ability to deliver services and to meet the nationally mandated access and waiting time standards for CYP-ED must be considered.
- BEAT are producing Norfolk specific promotional materials and promoting their range of support services more proactively and frequently. These include carers peer support, the BEAT national helpline and online support groups for those people living with or affected by eating disorders.

Actions explored and currently unviable / unable to progress

Exploration of sourcing appropriately skilled staff from other services / providers:

- Assistance from Cambridge Community Eating Disorders team explored - they are not sufficiently staffed to be able to offer any assistance.
- NSFT services were unable to release any capacity from their CBT trained staff
- CPFT services were unable to release any capacity from their CBT trained staff
- Exploration with private providers of eating disorders and CBT therapies

Other options explored to approach provision alternatively

- On line/telephone CBT resources from IESOI digital was explored. The proposition was not financially viable for them due to the relatively low patient numbers involved.
- BEAT considered the opportunity to offer a manual-based guided self-help service to people with new presentation of normal weight BN / BED. Due to staff resourcing and the additional training needed, this was seen as a long term project and not something which could be provided as a short-term offer.
- Local services with CBT trained staff have been approached to explore any available capacity to deliver a manual-based 10 session CBT (CBT-T) for people with BN. The appropriate services approached do not have the capacity to undertake this work.

Expected resolution:

Based on the outlined recruitment/staffing in section 2.2, NCEDS trajectory provides information to support the position that they will be able to resume normal services, with a removal of the temporarily raised acceptance criteria, by the end of quarter 2 in 2019/20.

Adult Eating Disorder Services (Great Yarmouth and Waveney) – Norfolk and Suffolk NHS Foundation Trust

The Adult Community Eating Disorder Service in Great Yarmouth and Waveney is commissioned to provide assessment and treatment to service users over the age of 18, with mild to severe eating disorders such as anorexia nervosa, bulimia nervosa, and atypical eating disorders including binge eating disorder

The GYW adult team accepted 68 referrals in the 12 months to June 2018.

The contracted response time from referral to assessment is: 4 working days of referral if the need is identified as urgent; or 20 working days if the need is identified as routine. These mirror the adult service for Central & West Norfolk.

The adult eating disorder service for GYW reports that the service is currently meeting waiting time targets and as such have no waiting list.

Children and Young Peoples Eating Disorder Service (Norfolk and Waveney) - Norfolk and Suffolk NHS Foundation Trust

Children's & Young Peoples Eating Disorder services are subject to national Access and Waiting Time Standards (AWTS), which adult's services are not.

These are as follows:

- National Institute for Health and Care Excellence (NICE)-concordant treatment should start within a maximum of 4 weeks from first contact with a designated healthcare professional for routine cases and within 1 week for urgent cases.
- The national delivery tolerance level for both Access Waiting Time Standards has been set at 95% from 2020. Local performance for Children's and Young Peoples Eating Disorder Access Waiting Time Standards performance is set at 95% currently.

Data against this Access Waiting Time Standard is submitted to NHSE ahead of local validation, which has led to NHSE published data giving a poorer representation of delivery than is locally agreed. We have been assured by the provider that, from the end of 2018, the validation timeframe has been significantly reduced and therefore CCGs expect data submissions to NHS England to be validated and accurate. Locally validated data shows that delivery against the:

- Urgent Access Waiting Time Standard performance sits at 92% for the 12 months to June 2018 – this includes one breach;
- Routine Access Waiting Time Standard performance sits at 80% for the 12 months to June 2018 this includes a period of time in which the Children And Young Peoples Eating Disorder Service (Norfolk and Waveney) Norfolk and Suffolk NHS Foundation Trust was experiencing a significant vacancy level, which impacted performance.

Referral levels during this same 12 month timeframe totalled 122 accepted referrals.

The level of risk for the Child or Young Person living with an Eating Disorder is assessed using the Junior MARSIPAN assessment, as set out in figure 1 – a complex interaction of physical, biochemical, psychological and behavioral factors.

	Blue (low risk)	Green (moderate risk)	Amber (alert to high concern)	Red (high risk)
BMI and Weight	<ul style="list-style-type: none"> Percentage median BMI >85% No weight loss over past 2 weeks 	<ul style="list-style-type: none"> Percentage median BMI 80-85% Recent weight loss of up to 500g per week for 2 consecutive weeks 	<ul style="list-style-type: none"> Percentage median BMI 70-80% Recent loss of weight of 500-999g per week for 2 consecutive weeks 	<ul style="list-style-type: none"> Percentage median BMI <70% (approximately <0.4th BMI centile) Recent loss of weight of 1kg or more per week for 2 consecutive weeks
Cardiovascular health (depending on age and gender)	<ul style="list-style-type: none"> Heart rate >60bpm; normal sitting BP; Normal orthostatic cardiovascular changes; normal heart rhythm 	<ul style="list-style-type: none"> Heart rate 50-60bpm; Sitting BP systolic 98-105mmHg and diastolic 40-45mmHg; Presyncope symptoms but normal orthostatic cardiovascular changes; Cool peripheries; Prolonged periphery capillary refill time (normal central capillary refill) 	<ul style="list-style-type: none"> Heart rate 40-50bpm; Sitting BP systolic <0.4th centile (84-98mmHg depending on age/gender) and diastolic <0.4th centile (35-40mmHg depending on age/gender); occasional syncope; Moderate orthostatic cardiovascular changes (fall in systolic BP of 15mmHg or more within 3 minutes of standing or increase of heart rate up to 30bpm) 	<ul style="list-style-type: none"> Heart rate <40bpm; History of recurrent syncope; Fall in systolic blood pressure of 20mmHg or more, or below 0.4th-2nd centiles for age, or increase in heart rate >30bpm); irregular heart rhythm (does not include sinus arrhythmia)
ECG abnormalities	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Normal except expected abnormalities relating to medication or family history 	<ul style="list-style-type: none"> Prolonged QTc interval 	<ul style="list-style-type: none"> Prolonged QTc interval; evidence of tachy / bradyarrhythmia; evidence of biochemical abnormalities
Hydration status	<ul style="list-style-type: none"> Not clinically dehydrated 	<ul style="list-style-type: none"> Fluid restriction; Mild dehydration 	<ul style="list-style-type: none"> Sever fluid restriction; Moderate dehydration 	<ul style="list-style-type: none"> Fluid refusal; Sever dehydration
Temperature			<ul style="list-style-type: none"> <36% 	<ul style="list-style-type: none"> <35.5°C tympanic or 35.0°C axillary
Biochemical abnormalities			<ul style="list-style-type: none"> Hypophosphatemia Hypokalaemia Hyponatraemia Hypocalcaemia 	<ul style="list-style-type: none"> Hypophosphatemia Hypokalaemia Hypoalbuminaemia Hypoglycaemia Hyponatraemia Hypocalcaemia
Disordered eating behaviours		<ul style="list-style-type: none"> Moderate restriction; bingeing 	<ul style="list-style-type: none"> Severe restriction (<50% required intake); vomiting; laxatives 	<ul style="list-style-type: none"> Acute food refusal or estimated calorie intake 400-600kcal per day
Engagement	<ul style="list-style-type: none"> Some insight; motivated; ambivalence towards changes required for weight gain not evident in behaviour 	<ul style="list-style-type: none"> Some insight; Some motivation; Ambivalence towards changes required to gain weight but not actively resisting 	<ul style="list-style-type: none"> Poor insight; Lacks motivation; resistant to changes required to gain weight; parents unable to implement meal plan advice 	<ul style="list-style-type: none"> Violent when parents try to limit behaviour or encourage food / fluid intake; parental violence in relation to feeding
Activity / exercise (in the context of malnutrition)	<ul style="list-style-type: none"> No uncontrolled exercise 	<ul style="list-style-type: none"> Mild levels of uncontrolled exercise (<1 hour per day) 	<ul style="list-style-type: none"> Moderate levels of uncontrolled exercise (>1 hour per day) 	<ul style="list-style-type: none"> High levels of uncontrolled exercise (>2 hours per day)
Self-harm and suicide			<ul style="list-style-type: none"> Cutting or similar behaviours, suicidal ideas with low of risk of completed suicide 	<ul style="list-style-type: none"> Self-poisoning, suicidal ideas with moderate to high risk of completed suicide

Figure 1: Junior MARSIPAN used by CYP-ED as criteria for assessing urgency

3. Voluntary / third sector services

Eating Matters is commissioned to deliver services to adults over 18 years old with mild eating disorders – classified as mild as per table 1 - by all Norfolk & Waveney CCG's - but in two separate arrangements. The Central & West system have a block contract arrangement, whereas GYW have a sessional arrangement with Eating Matters. The target group for Eating Matters is those people with Mild to Moderate Eating Disorders

In the Central & West system, in the 12 months to June 2018 Eating Matters accepted 197 adults into their service, 83 people were referred from NHS sources.

During the five years from 2012/13 to 2017/18 Eating Matters have seen a three-fold increase in the numbers of referrals received and accepted. The service has responded to increasing demand by expanding the space capacity within their current premises and recruiting additional therapists.

For 5 months, from June to November 2018, Eating Matters were unable to accept adult ED self-referrals, due to the increasing waiting lists as a result of increasing demand. Reflecting the increasing demand and to maintain a focus on prevention and early intervention, the CCG's of Central & West Norfolk agreed a funding increase for Eating Matters, to take effect from 1st April 2019. This increase reflects a funding uplift of over 56% for the service, to support ongoing capacity to provide support for individuals referred by NHS sources.

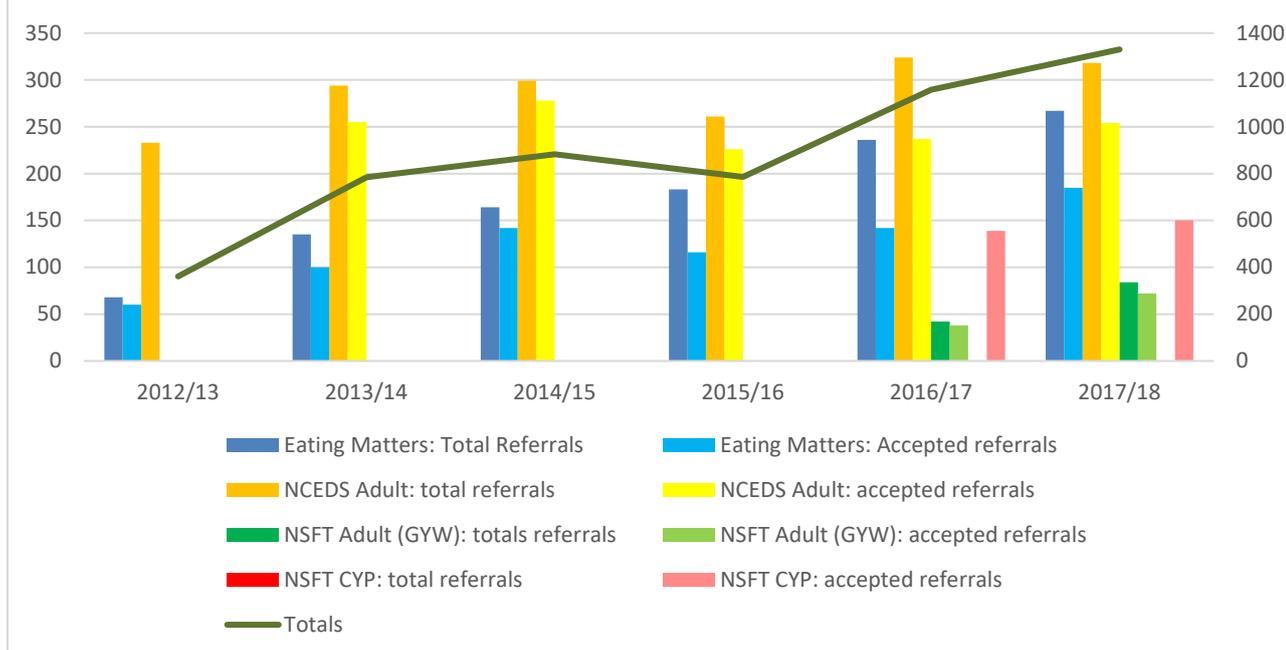
As of mid-March 2019, Eating Matters waiting list & times is as follows:

- In active service: 140
- Waiting list: 47 (20 assessed & awaiting interventions, 25 assessment arranged for March/April, 2 assessment to be arranged)
- Average waiting time: 6 to 8 weeks from referral to intervention starting

4. Demand for all services

The following – figure 2 - provides a picture of the trend in demand for eating disorder services in Norfolk & Waveney – noting that (a) the ways by which some aspects of demand is measured, and (b) the data collected by services has altered during the time period given:

Figure 2: Norfolk & Waveney Eating Disorders System - Picture of Demand



5. NHS England Specialised Commissioning

NHS England currently commission inpatient treatment (tier 4) for eating disorders, for adults and children & young people, through the Specialised Commissioning functions.

For Adults with an Eating Disorder requiring a specialist inpatient treatment (Tier 4) the system is that the referring community provider has to identify appropriate units for admission, those that meet the patient's specialist needs and which of these have availability, before making applications and maintaining contact with each unit as to a bed becoming available.

In Norfolk & Waveney commissioners have coordinated discussions with NHS England to provide increased oversight and communication over this process, to provide NHS England with awareness of demand. During 2018 NHS England introduced a single referral form for the inpatient beds, which NHS England commission. This aided the process somewhat, and defined the expected response times to referrals: emergency within 24 hours; urgent within 7 days.

The **Children And Young Peoples Eating Disorder Service (Norfolk and Waveney) - Norfolk and Suffolk NHS Foundation Trust** tier 4 specialised commissioned beds are managed through NHSE teams, who support the routes into specialist beds, via Care Managers, through to tier 4 units.

Adult services link to inpatient treatment

Local data identifies that during the 12 month period to June 2018, the average waiting time for an adult Eating Disorder inpatient unit was almost 18 days. Some of these waits will be affected by patient choice for agreeing to admission and/or the unit of admission. The longest wait was 49 days, for a patient with complex needs who was referred from the acute hospital, from which their discharge was delayed due to the wait for the ED specialist inpatient bed.

NHS England will provide further data on the specialised commissioned eating disorders inpatient services.

CYP services link to inpatient treatment

Data is not readily collected to provide an average waiting time from referral to access of a specialist inpatient eating disorder unit placement for children and young people. The process of referral to accessing a bed often includes a period of time during which the person referred is not wholly ready for admission e.g. they may be still receiving acute medical care in an acute hospital. Additionally, eating disorders beds are utilised where an eating disorder is not the primary mental health issue, rather it forms part of a complex presentation of interlinked health problems. But, due to the nature of the eating disorder and the risks it poses, general mental health units are often unable to provide the care required for those with a complex presentation for which eating disorder is only a, often non-primary, part.

There are set performance indicators by which those tier 4 providers, acting as gatekeepers for specialist inpatient beds, must make a decision on the approval / non-approval of a referral to specialist commissioned inpatient beds. Norfolk & Waveney has also seen a re-design of, and increase in inpatient CYP-ED beds during the last 12 months, making access to care locally more readily available.

NHS England will provide further data on the specialised commissioned eating disorders inpatient services.

6. Primary Care

Whilst under the care of the Adult community Eating Disorders services some patients, particularly those with associated medical risks, will be identified as requiring on-going monitoring from primary care. As a result a service is needed for the physical health monitoring of patients with eating disorders. This is provided as a shared-care service for adults, under a Locally Commissioned Service arrangement, which intends to be easily accessible, locality based and delivered in a GP practice environment. Medical monitoring for children and young people ordinarily takes place in Primary Care in partnership with CAMHS Eating Disorder services

In 2012 the Norfolk & Waveney Local Medical Committee (LMC), which represents all GP's in Norfolk & Waveney, cautioned members against undertaking the medical monitoring of patients with eating disorders without an agreed shared care agreement. It made this recommendation on the grounds of:

- Patient safety, on the basis of GP's clinical skills & clarity of guidelines to follow;
- Lack of access to appropriate step-up service(s);
- This service falling outside of the core General Medical Service contract;
- Costs of service provision.

Since this time each CCG has made arrangements with its GP's for the provision of adult medical monitoring services, and each CCG has encountered varied levels of engagement from primary care. This has led to variation between each CCG in the arrangements for provision of this service, with provision in some areas being more challenging to manage. North, Norwich and South CCG areas have strong Primary Care engagement with the shared care arrangements in place whereas in the West CCG and Great Yarmouth and Waveney areas currently Primary Care engagement is less formalised. The creation of a shared care arrangement in these areas is in progress.

Although there are variations between CCG's the model of delivery in Norfolk & Waveney is held up as a best practice example within the Eating Disorder services in the East of England and nationally

7. Acute Hospitals & MARSIPAN

In order to support the safe care of people with severe anorexia nervosa who are admitted to general medical units, the Royal College of Psychiatrists established a working group to give clear guidance on the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN). The vision was that this guideline then forms "*the basis of local policies*", in order to provide the safest acute medical care and stabilisation in instances of very severe eating disorders.

Norfolk & Waveney has established MARSIPAN policies for adults and children & young people, which have evolved, via multi-stakeholder working group, into additional resources to support the care, treatment and pathways of people admitted to acute hospitals. These stakeholders are now working to harmonise, as far as possible, the policies across the Norfolk & Waveney system, and to coordinate work across all ages of service users.

8. Transfers & transitions

There are a number of places where people with eating disorders transfer or transition between services. Possibly the most significant transition point is that between Children and Young Peoples Eating Disorder Services and Adult Eating Disorder services. In the Central & West Norfolk system, the Children and Young Peoples Eating Disorder Services (NSFT) and Adult Eating Disorder Service (NCEDS) work collaboratively, for a 6 month period until transition at the age of 18 years, as clinically indicated and dependent on individuals being in active service at the age of 17 and half years. This transition is managed as a pathway individual to each patient's needs, but will include typically an agreed joint meeting, an assessment and transfer Care Programme Approach. The services meet each quarter to discuss any transitioning / upcoming transition cases formally, with communication about individual cases in-between.

There are other points of transfer between services, such as when an individual moves from a generic mental health team, moves to the area while in treatment or is discharged from a period of inpatient care. The risks and needs of transfer are assessed, incorporating NICE quality standards and other relevant recommendations wherever appropriate and feasible. People who are in transfer in these circumstances will be considered for treatment as a priority. This is a different categorisation to urgent or routine, as the continuation of treatment may take precedence to the usual criteria for triaging in this way.

9. Finances

The health system in Norfolk & Waveney spent circa £2.4m on specific eating disorders services in 2017/18. These costs do not include the expenditure for specific eating disorder services which cannot be extrapolated out from baseline funding within block contracts, such as the part of Children and Young Peoples Eating Disorder Services which is included in Norfolk and Suffolk NHS Foundation Trust block contract. Neither do they include the cost of services delivered within the acute sector, namely at the Norfolk & Norwich University Hospital, the James Paget Hospital and the Queen Elizabeth Hospital.

10. Benchmarking with other services

Adult Eating Disorder Services (Central & West Norfolk) - Norfolk Community Eating Disorder Services (NCEDS)

In 2016/17 Cambridge and Peterborough NHS Foundation Trust took part in a national benchmarking exercise, undertaken by the NHS Benchmarking Network. The following was highlighted of Adult Eating Disorder Services (Central & West Norfolk) Norfolk Community Eating Disorder Services (NCEDS):

Interventions: 5 of the 6 top reported interventions (NICE concordat) are provided

Referrals: receive higher than average number of referrals (65 per 100,000 population). The acceptance level against these referral levels is 3 points lower than the average reported acceptance rate, a rate which is consistent with other community mental health services.

Caseloads: caseloads are below the mean average and in line with median reported caseloads.

Waiting times: are identified as better than the average 6 week waiting time for assessment, from referral.

Staffing: slightly lower than average staffing levels. The teams were identified at the time as heavily staffed with clinical psychology compared to others services.

Children's & Young Peoples Eating Disorders – Norfolk & Suffolk Foundation Trust

To date, no benchmarking has been identified for CYP ED services which will provide for a similar comparison to that for adult services at this time. However, in comparing the access and waiting times data, we can demonstrate that the Children's and Young People's Eating Disorders services, provided by Norfolk & Suffolk Foundation Trust, across Norfolk & Waveney compares as follows:

	Norfolk & Waveney CYP-ED service		Eastern Region performance		UK performance	
	Urgent	Routine	Urgent	Routine	Urgent	Routine
Q2 2018/19	92%	80%	83.1%	86.7%	81.3%	80.2%
12 months to end Q3 2018/19	95.8%	68.1%	77.8%	81.6%	78.9%	82%

11. Further developments

Further to the previously outlined measures being taken to address the immediate implications of the change to the acceptance criteria in the NCEDS service, there are a number of additional developments in various stages. The following provides an overview of these developments:

- The East of England Strategic Clinical Network for Eating Disorders, of which the Norfolk & Waveney commissioners are regular attendees and one of few commissioners in attendance, are exploring implementing a peer review process for services. This would enable services to formally explore their services effectiveness and efficiency with critical friends, in recognition of a lack of other formal benchmarking options.
- Norfolk & Waveney commissioners and providers are actively engaging with the new models of care developments, which are in their infancy in the area.

- Norfolk & Waveney have proactively engaged with NHS England commissioners of tier 4 eating disorders provision in attempts to review current processes and share information on the local implications of current processes.
- We are in a process of reviewing and revising our model of service delivery, considering the services across the Norfolk & Waveney footprint and across the span of all ages. We are developing a coproduction approach to this process.
- We are engaged with Cambridge and Peterborough NHS Foundation Trust in a process of external review to compare the current service with high performing models elsewhere in the country.
- We are working with the Local Medical Committee to look at potential options as regards the arrangements for medical monitoring in Primary Care

12. Summary

Eating Disorders is a complex issue, with many factors impacting on the individual such as traumatic experiences in early life and the influence of social media. The condition interfaces the individual's Physical Health, Psychiatry and Psychology. The condition maybe short term but also can be medium and long term and chronic. Eating disorders has one of the highest mortality rates for any Psychiatric condition, as such it is distressing for all concerned, the individual, family and friends and the clinical staff involved in the care of the individual.

Factors, as outlined above, are seen as some of the reasons why recruitment into this area of specialism is becoming increasingly difficult. The workforce position that was the main factor for the position Norfolk Community Eating Disorder Service (NCEDS) experienced. Repeated recruitment activity was unsuccessful until March 2019 when 3 new specialist members of staff were recruited. Staffing and recruitment in this specialist appears to be variable across the country, across all age ranges therefore the position can alter rapidly. The trajectory to re-establish the original criteria for access to the service is planned for July 2019.

NICE guidelines provide for a number of different treatment options, dependent upon the individual's needs, one of the main options being CBT-E but others can be used. Norfolk CCG's are currently working with providers to explore potential options to increase flexibility and options for skill mix.

Specialist eating Disorder services are mainly constituted of specialist Psychiatry and Psychology provision, which are the main component of treatment provision. The Specialist Eating Disorder service works in partnership with Primary Care who are requested to work with the specialist services to undertake such activities as blood testing, weight monitoring, Squat testing and ECG's, if required.

The provision of the Primary Care element is not a requirement in the core Primary Care contract hence this service is requested to be considered by Primary Care under a Locally Commissioned Service arrangement. However individuals with an Eating Disorder may also have other concurrent physical health conditions hence strong linkage and oversight by Primary Care is a key aspect of the care pathway.