Oxford Health
NHS Foundation Trust

Oxfordshire Adult Eating Disorder Service
Members' briefing for Oxfordshire HOSC

May, 2021

Introduction

All eating disorders are a group of severe mental health disorders which have the highest risk of mortality of all Severe Mental Illness (SMI). Comorbid alcohol and substance misuse, type 1 diabetes and a history of self-harm increases the risk of mortality in all diagnostic groups.

Most adults with eating disorders have complex physical and psychiatric comorbidities which have a major impact both on risk and treatment outcomes and need to be treated according to the relevant NICE guidelines.

The most common mental health comorbidities in anorexia nervosa include depression (40-70%), anxiety (50-70%), obsessive compulsive disorder (OCD) (30%), and post traumatic stress disorder (PTSD) (20-30%).

Up to 35% patients with chronic anorexia nervosa are on the autistic spectrum and these patients need a specific treatment pathway. Physical risks are related to acute and chronic malnutrition, which often cause admission to acute medical hospitals.

Research suggests that 80-90% of people with eating disorders are not known to specialist services. There are challenges inherent to the care and treatment of people with an eating disorder which lead to delays in accessing specialist help.

Strategic and national context

In the NHS Long Term Plan there is commitment across multiple stakeholders to improve both timely access to, and the quality of evidence-based treatment for people across all age groups in the provision of eating disorder services.

In 2019, NHSE published the commissioning guide for adult eating disorder services, which is the blueprint for developing Adult Eating Disorder Services (AEDS) as part of the Long Term Plan (LTP). This guidance established a clear rationale for localities to focus on improving care for adults with eating disorders as outlined below:

NHSE AED Commissioning guidance (2019)

Community Eating Disorder (ED) services should:

1. Provide evidence-based treatment, care and support for the full range of eating disorder diagnoses, including binge eating disorder and Other Specified Feeding or Eating Disorders (OSFED).

2. Accept all presentations from people who present for the first time to those with long-term problems, regardless of weight or BMI (body mass index).
3. Have the skills to provide care across the lifespan, from younger people to older adults.
4. Provide medical monitoring.
5. Offer intensive community treatment, or be able to support day patient treatment, to reduce unnecessary or inappropriate inpatient admissions.
6. Be proactive in engaging people in treatment as soon as possible, as well as those who are returning to active treatment following a period of recovery.
7. Support and empower families, partners, carers and the person's support network.
8. Offer advice, support and consultation to other services involved in a person's care.
9. Provide coordinated care (see Section 2.4) work with other services to reduce and prevent gaps in care during service transitions (age-related, geographical or community to inpatient transitions); using clear protocols and joint working agreements.
10. Respond appropriately to issues relevant to competence, capacity, consent, safeguarding and information-sharing.
11. Have clear processes around managing risk and safety as well as unattended appointments (including clear follow-up protocols to engage a person and prevent inappropriate discharge).
12. Provide appropriate clinical supervision to ensure professionals remain competent to deliver evidence-based treatment.
13. Improve awareness of the service in the community, the importance of early identification and reduce the stigma around eating disorders to increase help-seeking in the local population.

Key principles of the LTP relevant to individuals with eating disorders are:

1. Community-based care closer to home
2. Increasing access to psychological therapies (IAPT).
3. Personalised and trauma-informed care.
4. Improved physical health care.
5. Better integration of health and social care systems (towards ICSs and PCNs) to maximize continuity of care.
6. New focus on those too severe for IAPT but not severe enough to meet secondary care thresholds (this includes ED)
7. Aiming to eliminate exclusions based on diagnosis/complexity and avoid unnecessary repeat assessments or referrals.
8. Particular attention to those 18-25 needs lead not age led care (role out of FREED model).
9. Workforce expansion and integration with primary care

Service overview

Local context:

Oxford Health NHS Foundation Trust offers a wide range of specialist eating disorder services across all ages and different localities. The Oxfordshire community AEDS Team is one of the services commissioned to provide a specialist eating disorder service by the CCG. There is no specified activity level in the current contract though the number of referrals accepted by the service is disproportionally high relative to the local population.

1. The Adult Community ED service has seen year on year increase in the rate of referrals since 2016,
2. Historically, the service was commissioned for moderate to severe eating disorders until 2020, at which point all ED presentations were considered for acceptance to the service, since early intervention yielded better long-term outcomes.
3. Due to high demand and insufficient capacity, the service has been in business continuity measures since March 2020 (this coincided with the pandemic) and only those patients presenting with severe and extreme eating disorders would be treated by the team, (with some supporting consultations offered to GPs since March 2022). At the time, the service had 5 whole time equivalent staff and approximately 500 referrals, with an existing caseload of over 500 patients and 40-week treatment programmes, and this put unrealistic demands on the service. This is clearly not an ideal position and not part of a long-term plan.
4. Despite the exclusion criteria, referral rates remain high, suggesting increasing morbidity since the pandemic. This is reported elsewhere in the UK.

The impact of the pandemic

The COVID-19 pandemic has further compounded the existing challenges. Services across the South East are reporting that referrals of eating disorders and/or the acuity of presentations have significantly exceeded pre-COVID levels. Increases in the acuity and levels of risk in those presenting to ED (Eating Disorders) services across the lifespan resulting in increasing waiting times for admission to specialist hospitals have placed extreme pressures on community ED services and acute hospitals.

Locally this has been our experience and the service has seen both increased acuity and late presentations contributing to complex and high risk caseloads along with reduced capacity in the workforce due to a number of factors, including infection control measures, staff shielding or quarantined, high sickness levels, and high turnover.

A further factor has been accessing appropriate space to use whilst maintaining social distancing and staff/patient safety. The impact of COVID-19 has led to higher risks in the service and longer waits for treatment as therapists time is dedicated to risk management and care co-ordination resulting in capacity not meeting demands.

There is increased demand on primary care for the physical health components of care resulting in a fragmented service that is unable to meet the complex needs of this group.

Inpatient referrals have increased, reflecting the increase in
acuity and lack of capacity to deliver effective treatment in the community.

Expansion

The Oxfordshire AEDS service has some key strengths. The service is well known for its expertise in Cognitive Behavioral Therapy for Eating Disorders (CBT-ED) and has strong links with the CBT-E centre CREDO and University Department of Psychiatry.

The team has multiple staff members who are highly experienced in working with eating disorders. The team is delivering internal training to all new staff as well as participating in the HEE funded AEDS whole team training programme, which started in March 2021.

The community team has strong historical links with the inpatient unit, Cotswold House at Warneford Hospital, Oxford, which is commissioned by NHS Specialist Commission. In recognition of long-term underfunding, the team received additional investment in 2020 with the aim of improving service provision and enabled a plan for expansion, however this also collided with the onset of the COVID-19 pandemic and a surge in the number of referrals as well as the lack of suitable staff to recruit.

In March 2020, the team consisted of 5.5 wte establishment following several resignations, through retirement, promotions, family circumstances and other issues within the team. The financial resources were to fund the additional posts which would increase the whole establishment to 17.3wte and expand the multi-disciplinary professional representation.

There have been challenges to recruitment of the identified posts and there remain some gaps in the service although there has been some greater success in recruiting by the end of May 2021. Some of the post descriptions have been changed due to inability to fill the original type but the overarching plan to develop the service through team expansion remains the same.

Referrals and waiting times

The 2019 NHS Digital adult prevalence data suggest that more than 17200 people in Oxfordshire suffer from an ED. The Oxfordshire AEDS only received about 500 referrals in recent years but since March 2021 has been closed to ED of lower acuity.

This local referral data corresponds with the literature, which suggests up to 90% of patients with ED are not known to secondary services. This highlights that the demand may increase significantly in the years to come.

The numbers of adults presenting with ED in Oxfordshire are disproportionally high and the presence of two large universities will increase numbers. A survey of Oxford University suggested that up to 1,800/30,000 Oxford students may have an ED, but only about 80/1,800 students get referred to the Oxford adult ED service per year.

There has been a rising trend in referrals between 2013-2020, averaging around 11% a year, prior to the introduction of business continuity measures in 2020. The table below shows

referrals over the past 3 years including number referred and numbers accepted (Source: TOBI):

Financial year	Total referrals	Total actioned	% accepted	% change
2016/17	397	337	85%	
2017/18	406	290	71%	+2%
2018/19	413	327	79%	+2%
2019/20	523	364	70%	+27%
2020/21*	467	313	67%	
Projected 21/22	644	**547 .4**	Based on 85%	2019 plus 2 11% increases

***decrease due to COVID and national trend of MH downturn Q1/Q2 pandemic as well as restrictions on referral acuity**

Comparing 17/18 to 20/21 shows a 14% increase in referrals, more realistic comparison is 17/18 to 19/20 with a 22% increase.

There are still considerable waits for treatment. It is difficult to pull this data from the Trust's Carenotes system in a meaningful way as those patients who are on the waiting list are actively monitored until formal treatment starts.

For the patients that are waiting, all high-risk patients are offered regular physical monitoring (weight check) plus brief psychoeducation/mental health review in addition to a risk management session while they wait for evidence-based treatment.

Details of waits for formal psychological treatments:

The service currently has substantial waiting lists for NICE-concordant psychological intervention.

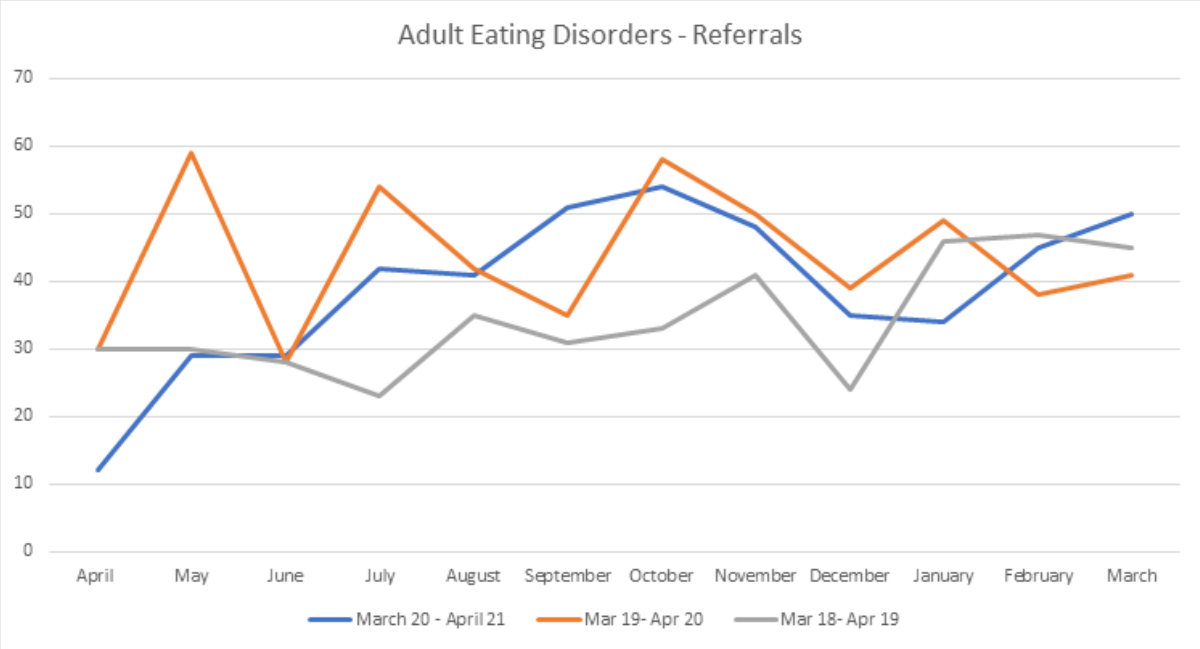
- As of March 2021, 47 individuals with **severe and high-risk eating disorders (priority group)** are waiting for NICE-concordant psychological interventions. 77% have a diagnosis anorexia nervosa (including atypical) & 23% have a diagnosis of bulimia nervosa or binge eating disorder. The expected waiting time for this group is currently 18 months. The longest wait is from June 2019. (23 months)
- A further 93 individuals who have **moderate severity** are waiting for NICE-concordant psychological interventions. The expected waiting time for this group is 24 months. The longest wait is from February 2019.
- There are also 13 individuals waiting for guided self-help, longest wait is from May 2020. Due to the severity of presentation, many individuals require active support and

monitoring by staff to mitigate risk. This leaves extremely limited capacity to deliver the psychological interventions that this cohort are waiting for.

There is limited evidence supporting the effectiveness of waiting list interventions, but we are looking at models being delivered across the country.

The Eating Disorders charity BEAT offers waiting list interventions and we are investigating if this would be something that could be commissioned to provide a service.

We are also considering other models being delivered across the country and exploring every opportunity that will provide patients with the best available treatments that are being developed and researched.



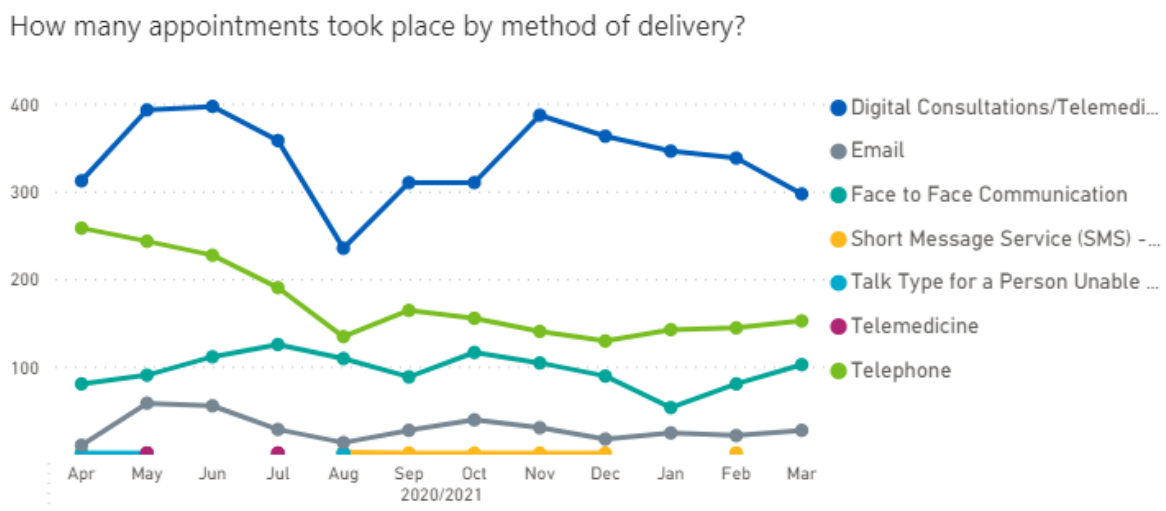
Team Activity

The contractual commissioned annual target for direct and indirect contacts per annum is in total 4,577 below shows that we exceeded that target for 2019/20

Year	Number of total Contacts Delivered
19/20	4681
20/21	4467

Digital Working

Throughout our response to COVID-19 the Trust rapidly introduced digital consultations via Microsoft teams. This enabled service provision to continue through COVID-19 restrictions.



Developments to date

In 2020, the Mental Health Investment Standard (MHIS) provided £500K of recurrent funding which allowed for significant development in terms of initiating the major transformation of the service model for Oxfordshire Eating Disorder Services, but this only went some way in developing the service as is needed.

Ongoing challenges to recruitment and retention in a specialist field that is in high demand (especially from the private sector) has led to creative ways to recruiting to posts and achieving the key roles to meet the service needs.

Some gaps still remain and an experienced locum psychiatrist has now been appointed, following a long period without a consultant medic within the community team, and we are

also looking to recruit an additional GP liaison role which will add considerable value to the medical input within the team.

We have appointed a permanent, experienced team manager, as well as an experienced senior psychologist. This is in addition to several key therapy roles, a lead nurse role, and development posts across a range of professional backgrounds to ensure there is a good career structure for staff and development opportunities for training within this specialist area of working.

It is important to ensure that the provision for this patient group considers the physical, functional, mental health and medical needs within the staffing structure and how the patient pathways support those needs.

The current position with staffing is 13.68 wte (whole time equivalent) in post and 7.4 wte vacancies.

All patients waiting for treatment are contacted six weekly for a check in and offered self-help guidance. If there are any concerns re their eating disorder presentation, patients are advised to see their GP for a physical health check. There is also a high-risk clinic that is available for complex patients.

In addition, we are looking at other opportunities: -

- considering online therapy offers.
- Gaining support from adult colleagues to use therapists time offering therapy to patients on the waiting list.
- The service has developed in-house training and participates in national training.
- The service has good links with the university: opportunity for building on CBTE, QI and innovation.

Summary of MDT capacity review

To deliver enough therapy contacts alone to provide NICE-concordant psychological treatment to those waiting and based on current referral trends would require 446 appointments per week. This is only a part of NICE-concordant care for adults with eating disorders.

Considering assessment appointments, care-coordination activities, joint appointments, support, and monitoring for those with longstanding eating disorders, medical and psychiatric reviews, attendance at tribunals, carer support etc. would require at least a 25% increase to this figure (558 total).

Based on referrals and those current waiting for treatment, recurrent investment in staffing capacity modelled on around 550 referrals a year would create an initial opportunity to deliver treatment to the patients on the waiting list at the same time as offering treatment at the current referral levels, allowing for a rise in referrals once business continuity measures

are lifted, further yearly increases, and the introduction of
FREED (First Episode Rapid Early intervention for Eating Disorders).

FREED

The **First Episode Rapid Early Intervention for Eating Disorders** (**FREED**) is an innovative service model that has offered support to over 1,200 16 to 25-year-olds. The FREED programme represents a key priority for implementation within Year 1 and 2 of the LTP ICS-wide CMHT plan. FREED is an early intervention service, based on the staging model and has been developed specifically to target adolescents and young adults (16-25 years) in the early stages of an ED (less than three years illness duration).

The FREED service model includes a rapid and proactive referral process, a holistic and non-stigmatising assessment (within two weeks of referral) based on a bio-psycho-social approach, followed by an evidence-based treatment plan (within two weeks of assessment). FREED has been shown to reduce total treatment costs and improve outcomes in young adults presenting with an ED.

In 21/22 we propose to capture baseline data and to establish FREED for those aged 17.5-21 in the first instance. Based on 2019 data this would equate to around 53 eligible referrals based on current AED referral criteria.

NICE-concordant treatments for Adults with ED range between 20 and 40 sessions in length depending on diagnosis. Modelling using the CReST tool (Demand and Capacity Tool) would suggest that for to offer an average of 30 session treatments, starting within 4 weeks of referral, the service would need capacity to offer around 40 NICE-concordant therapy contacts per week.

This is in addition to staffing the non-clinical aspects of FREED which include awareness raising, liaison with key stakeholders e.g., primary care and education and data tracking.

Clinical needs/pathways within the AEDS

Longstanding/Complex Pathway/ASD/Diabetes/High Risk

Service users with a severe and enduring or more complex presentations requires specific provision tailored to their needs. Individuals with autism spectrum disorder (ASD) or diabetes require management specific to their co-occurring conditions. Those with longstanding EDs are currently offered regular psychological support and monitoring appointments. This intervention is not time limited and is focused on improving quality of life, monitoring of eating disorder symptomatology (alongside the individual's GP) and preventing repeat hospital admissions.

These groups often require joint working with adult mental health teams around co-morbidities. Recent interviews with individuals who have experience or a longstanding ED and extended or multiple episodes of care suggest this group value (i) access to medical

monitoring (ii) peers support groups/links and (iii) support work to improve quality of life and (iv) access to formal psychological interventions if and when appropriate.

Adults with Eating Disorders in Acute Medical Settings

There has been recent reporting of year on year increases in bed use by eating disorder patients. This coupled with the fact that most adults want, and should, be treated in the community means that community services nationally are under increasing pressures and Oxfordshire Eating Disorder Service is no exception.

Individuals who are identified as requiring an inpatient admission will typically be very low BMI (under 14), often with abnormalities on bloods and other physical health investigations.

Therefore, the service is managing physically very unwell patients with the current challenges in capacity and without sufficient medical or dietetic input in the team. This can result in significant anxiety for staff in the eating disorder service, carers and the patient's GP, as bloods and other physical checks at this stage of the illness will need to be frequent, which can present a challenge of capacity to GPs. Interpretation and management of physical health at this stage can also present a challenge to GPs.

Proposed staffing and investment for 21/22

A further business case has been submitted to continue the work that has been started to meet the NHSE standards. This will continue in the forthcoming years and transform the Specialist Eating Disorder Services into a bespoke service meeting the needs of the population of Oxfordshire. The staffing structure is based on the ED capacity modelling and existing FREED implementation sites.

ED HOPE Tier 4 Provider Collaborative

In 2018, Oxford Health NHS Foundation Trust (OHFT) formed the Tier 4 Adult ED HOPE (Health Outcomes for People with Eating Disorders) Provider Collaborative (PC).

The PC is in shadow form currently until October 2021, NHS England South East are the commissioners until the PC goes live.

Upon go live, OHFT will be the lead provider for the Thames Valley Tier 4 Adult ED HOPE Provider Collaborative, covering; Buckinghamshire, Oxfordshire, Gloucestershire, Berkshire West and BSW (BaNES, Swindon & Wiltshire) partners include:

Current Inpatient Partners	Current Community partners
1. Oxford Health NHS FT 2. The Priory Group	1. Gloucester Heath and Care NHS FT 2. Berkshire Healthcare NHS FT 3. Oxford Health NHS FT

The inpatient units/beds within the provider collaborative footprint include:

- 8 bed Adult Eating Disorder unit in Marlborough, Wiltshire. (OHFT Provider)
- 14 bed Adult Eating Disorder unit in Oxford. (OHFT Provider)
- 8 bed Adult Eating Disorders Beds Priory Marlow (Independent Sector), NHSE commissioned 8 beds April 2021)

The Provider Collaborative will continue to develop a whole system, integrated approach which spans across health and social care. By managing the care pathway, we will be able to ensure that patients are cared for in an inpatient setting or via an 'out of hospital' service as close to home as possible. This will:

- Improve patient outcomes
- Reduce the burden on patient and families to travel long distances.
- Enhance continued engagement with community clinical teams.
- Encourage early therapeutic home leave.
- Minimise length of stay.
- Avoid admission.
- Increase patient flow and volume.

The Provider Collaborative will ensure that community and inpatient provision continue to work as an integrated pathway ensuring patient care is seamless, timely and appropriate to meet needs. Ensuring that the Provider Collaboratives multiagency approach supports developments to provide alternatives to admission and admission prevention.

Alternatives to admission

The Provider Collaborative clinical model includes the development of a number of alternatives to admission that will form part of the investment strategy for the PC, to invest funds where beds are not available to meet the demand by offering alternative evidence based approaches.

The Stepped Care Model approach is being considered for the provider collaborative, a CBT-E model intensity is chosen to meet patients individual needs (community, intensive home treatment or hospital treatment). It is a stepped care approach to meet the needs of each patient, reducing inpatient admissions and length of stay.

Our team in Oxford has been working on adopting the model

Table 1. Summary of the stepped care CBTE model

Recovery focus:

1. to restore to a **healthy weight**
2. to identify and correct the mechanisms that maintain the **psychopathology**
3. to ensure that the changes achieved are **lasting**

Principles

1. Least restrictive
2. Patients are treated as adults
3. Staff and patients work towards a common goal
4. Whole system – stepped care – based on evidence based psychological treatment
5. Time limited admission (13 weeks for full weight restoration and 7 weeks day treatment for stabilisation – followed by outpatient CBTE (in total 40 sessions as per NICE Guidelines)

Cost/Benefit Analysis

Benefits of investment

This will deliver increased quality through providing a service response time that ensures equity with Children and Young Peoples services of 1 week from referral to treatment for urgent cases and 4 weeks for routine. There will then be access to a range of evidence-based treatment pathways including individual and group therapy.

The clinical benefits of this model will include:

- Increase in provision to meet the demand of projected 548+ referrals per annum.
- Increase in service user, carer, GP/referrer and staff satisfaction.
- Parity between CYP EDS and adult EDS
- Improvement in clinical outcomes across all presentations
- Reduced pressure on GPs, advice on interpretation and management available
- Meeting core functions of an effective AEDS as outlined in NHSE Guidelines.
- Offering FREED pathway that will provide the service with an early intervention focus that should support savings further on as people will not have a lifetime of experiencing acute mental health services.
- Meeting the need of SEED individuals
- Offering effective student pathway
- Offering carers' support
- The backlog of referrals will be addressed.