



Improving lives **together**

Norfolk and Waveney Integrated Care System

# Eating Disorders

An All-Age Strategy for Norfolk & Waveney

*September 2022*

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## Executive summary

Eating disorders (ED) are complex mental health conditions where people use the control of food to cope with feelings and difficult situations. Intrusive ruminating thoughts can result in avoidance of social situations and isolation for affected individuals resulting in low self-esteem. Unhealthy eating behaviours may include eating too much, or too little, or worrying about weight or body shape. Anyone can experience an eating disorder but it most commonly affects those between 13 and 17 years old. Eating disorders can have serious implications, including risk of death, impaired health, psychiatric comorbidity and impacts quality of life for the individual and those around them. However, with treatment most people can recover from an eating disorder. We also know that getting treatment earlier provides a better chance of recovery<sup>1</sup>.

The NHS Long Term Plan (2019) sets out the need to transform and invest further in eating disorders services, for both children and young people (CYP) and adults. At the same time, since 2020 and the start of the COVID-19 pandemic, the demand for eating disorder services has almost doubled from pre-pandemic levels and more people have been more unwell when they first sought help. This has an impact across all parts of our health and care service, just as it impacts all areas of an individual's life.

Since our current services were first implemented, there has been key changes in guidance from NHS England and the National Institute for Health and Care Excellence, and recognition of new types of eating disorders, which highlight the requirement to respond to changing needs and best practice. Also within this landscape of change and drivers for improvement is the need to reflect the learning from the Parliamentary and Health Service Ombudsman (PHSO) and Prevention of Future Deaths report (PFD).

That is not to say that Norfolk and Waveney has been standing still in regards to the expansion and development of provision for people with eating disorders. Since 2019/20 we have developed focused work with services and the system to expand the capacity and remit of provision, specifically to include medical support, earlier interventions and to strengthen and expand specialist teams.

Through this strategy and the way it has been brought together by partners from across our system, we have initiated the process of collaborative system review and ambition setting for the provision of services to people with eating disorders in Norfolk and Waveney. This has created strength and unity in our aims and routes to achieving them.

We will be ambitious. We will aim to ensure the provision offered to the population across Norfolk and Waveney is the best it can be. We will do this by not only focussing finances or exclusively developing the specialist services needed, but by considering how we meet needs across our whole system and working alongside Rethink Mental Illness and other partners at the earliest opportunity will allow us to reach out to our

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<sup>1</sup> [Overview – Eating disorders - NHS \(www.nhs.uk\)](https://www.nhs.uk)

underserved communities, accessing community champions and others to facilitate engagement. This will ensure that we meet the needs across our whole system and that eating disorders is everyone's business.

**Cath Byford, Deputy Chief Executive Officer & Chief People Officer, Norfolk and Suffolk Foundation Trust**

Cath Byford was Chief Nurse for Norfolk and Waveney Clinical Commissioning Group, at the time of the development of the strategy. Latterly, this strategy has been endorsed by Tricia D'Orsi, Director of Nursing at Norfolk and Waveney Integrated Care Board.

Co-authored by:

Dr Ardyn Ross, Diane Smith, Rebecca Mann and Jeremy Bell – members of mental health transformation teams at Norfolk and Waveney Integrated Care Board.

**Our thanks in developing and co-producing this strategy go to:**

Experts by experience – people who have experienced an eating disorder, either through direct lived experience or as parent, carer, friend or loved one – who have been critical in keeping the needs of individuals at the heart.

NHSE/I Regional Eating Disorder leads – providing valuable national and regional context and involvement in the drafting of this strategy.

Local service providers, those delivering specialist eating disorder services and also our GP's, hospitals and community services.

The East of England Eating Disorder Provider Collaborative, which now oversees specialist inpatient care.

Local Authority representatives, in Norfolk and Suffolk County Councils.

## Foreword

As an expert by experience and Community Leader, it is a privilege to have been invited to contribute towards this strategy, as part of the Community Transformation Programme.

With my own eating disorder experience, alongside severe mental health challenges, I am very encouraged to see the development of this all age strategy, utilising opportunities to 'make every contact count' and to provide seamless pathways of holistic care, across all services, at point of need, through integration with physical health and other mental health pathways, focus on early intervention, support of carers and families and upskilling the entire workforce.

I strongly welcome a collaborative approach to therapy, with health professionals engaging in clinical conversations and mutual learning and I look forward to utilising further important opportunities for experts by experience to become involved, alongside Rethink Mental Illness, and to consider how these experts can feed into the implementation of this strategy and connect with the workforce pathways.

I am very aware of the resilience and perseverance which my eating disorder mindsets nurtured in me, and the massive force for positive change this can be, when given the opportunity to channel it in the right direction. I feel that as we are able to support others to find their own pathways of recovery, there will be a stronger voice to promote hope, and influence far wider than just those currently suffering, and that we can begin to truly experience Community Transformation.

### **Helen Blake, Expert by Experience**

As Director of Nursing for the Integrated Care Board in Norfolk and Waveney, I wholeheartedly endorse the commitment to the transformational change described in this strategy. I celebrate the level of co-production which is evident throughout this strategy and will continue to inform delivery. Through continuing our collaborative working with all partners - including VCSE, social care and secondary care colleagues - the ICS is committed to deliver the ambitions set out in this document.

As I write this, we have already made progress to deliver some aspects of this strategy, including our intensive support services, joint working with VCSE organisations and our plans for supporting people with Avoidant and Restrictive Food Intake Disorder (ARFID). These pathways are well underway and will underpin much of the new service delivery. As Integrated Care System structures and plans develop, this document will ensure our ambition remains clear, and guides us. We are absolutely committed as a system to delivering the best possible care for people living with an eating disorder and those that support them.

**Tricia D'Orsi, Director of Nursing, Norfolk and Waveney Integrated Care Board.**

## Section 1 – The need for a strategy

Eating disorders are a range of psychological disorders characterised by abnormal or disturbed eating habits (such as anorexia nervosa). Recognised and defined in the International Classification of Disease (ICD11), eating disorders are serious mental illnesses and can have significant impact on an individual and those around them. An eating disorder can impact all aspects of a person's life – their physical, psychological, social and emotional health and wellbeing. At times, these effects can become life-long and life-limiting. Eating disorders have the highest death rate of all mental illness and it is estimated that over 1.6 million people in the UK are affected by an eating disorder. People with eating disorders benefit from a collaborative approach between a variety of sources including physical and mental health services and social support such as families, education, workplace and society generally.

It is recognised that early identification and prompt, person-centred responses to eating disorders, both early in illness and early in episode are essential in order to optimise recovery and reduce the duration of the illness. However, eating disorders often go undetected until the illness becomes more obvious and symptoms more entrenched. Awareness across our communities and in health and social care of both the illness and how, where and when to seek professional help is central to achieving better outcomes.

Prevention of eating disorders is a combination of enabling and promoting protective factors in the population; sociocultural factors in whole-of-population approaches; more targeted policies for at-risk groups; and specific health policies to guide development of integrated systems for people with complex conditions. Moving forwards, there must be a multi-layered system of prevention programs, frontline health responses, treatment and support services for the individual with an eating disorder and their families / carers.

People with eating disorders often present with varying symptoms, and the illness may follow a variable course, often with fluctuations in severity, acuity, complexity and risk, especially if it goes untreated. There is also growing recognition of the complexity of need and wide variety of eating disorder presentations. An eating disorder in conjunction with a severe mental illness, neuro-developmental disorder or learning disability results in a multi-layered complex which requires a carefully coordinated response.

In addition to this complexity is the need of individuals who have a challenge to eating which stems from a psychological basis different to the diagnosable eating disorders outlined by the ICD11. The path through services has been difficult to navigate for this group, and the Norfolk and Waveney system must agree a more coordinated approach to identifying and supporting the needs of this population group.

This complexity calls for a dedicated strategy to develop a shared understanding of the issues and a unified direction going forward. Additional to this, a multitude of

strategic drivers have brought about the need for a clear and cohesive strategy to drive the development of provision for people with an eating disorder, and associated disorders of eating, in Norfolk and Waveney. The key drivers include: the focus on adult eating disorder services, following the expansion of children and young people services for eating disorders; developing an Integrated Care System approach which brings together health and social care to support people to live well in their communities; NHS led provider collaboratives; and the learning and recommendations of investigations and into the deaths of people with an eating disorder.

These are explored in more detail as follows.

### 1.1. The NHS Long Term Plan (2019) & NHS Five Year Forward View

The NHS Long Term Plan, published in 2019, set out NHS England's priorities for the next decade and identified ways in which long term funding will be used. It formed a bridge with the *Five Year Forward View for Mental Health* (February 2016) and succeeds it. It has profound implications and possibilities for the whole of the nation's health. The Long Term Plan, and subsequent implementation and associated policy documents, set out a 'new service model' for mental health and has a recurrent theme to enable people to look after their own health more effectively. For eating disorders, these plans include:

- Continued investment in community eating disorders services for those aged under 19 years, to enable the standards for access to be met and sustained beyond 2020/21
- Improving the access to psychological therapies for people with an eating disorder
- Improving the availability of workforce with the skills needed to provide evidence-based treatments for adults with eating disorders
- Additional investment in adult eating disorders services, through transformation funding from 2021/22
- Testing and embedding a four-week waiting time standard for adults, from the point of referral to treatment.

### 1.2. NHS England & Improvement (NHSE/I) Guidance

#### a) Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care (2019)

In 2019, NHS England, with NICE and the National Collaborating Centre for Mental Health, published a new guidance document for Adult Eating Disorders. This guidance provides a framework for systems to understand key functions and delivery models for community eating disorders provision. This guidance identifies key aspects of a good eating disorder provision including:

- treatment and support should be evidence-based and outcomes should be measured
- all types of need (presentations) and ages should be catered for
- provision should include physical health monitoring and intensive support
- intensive community treatment, should be available in order to reduce unnecessary inpatient admissions
- engaging people in treatment expediently, both newly diagnosed and people returning to treatment
- ensuring that care is co-ordinated to prevent gaps in service provision during transitions such as age-related service changes
- raising awareness of the eating disorder services to improve earlier identification and reduce the stigma of eating disorders

#### b) Children & Young Peoples Eating Disorders Access & Waiting Times Standard (2015)

The Children and Young People's Eating Disorder standards set out, in 2015, the aims for accessing National Institute for Health and Care Excellence (NICE) concordant treatment for all people under the age of 19 years presenting with an eating disorder should access NICE concordant specialist treatment within the following timeframes:

- four weeks for routine cases
- one week for urgent cases
- 24 hours for emergency cases

The standards also set out other best practice and key requirements, including:

- The broader needs of families and carers should be supported
- Ensuring a dedicated ED team is available in the community, with appropriate staff numbers and skill mix, delivering evidence-based treatments
- Arrangements to support movement between services
- Outcomes for people should be monitored

### 1.3. National Institute for Health and Care Excellence (NICE) Guidance & Quality Standards

#### a) Eating disorders: recognition and treatment (NG69)

NICE Guidance sets out key principles for care and treatment of eating disorders, including:

- improving access to care
- equality of access
- consideration of difficulties that people with eating disorders have in speaking to healthcare professionals and staff about their eating disorder.
- receiving information and interventions tailored to age and development.



- treating the person as an individual
- earliest possible assessment and treatment
- that the needs, preferences and values of the person with the eating disorder should be considered alongside the clinical guidance

NICE Guidance provides details of the treatments which should be used for people with eating disorders (such as Anorexia Nervosa and Bulimia Nervosa) and these include psychological therapies such as Cognitive Behavioural Therapy Eating Disorders (CBTE) and Family Therapy (FT). Working collaboratively with other areas of healthcare are recommended particularly when a person with an eating disorder also has another condition (co-morbidity) to ensure that the person is supported holistically.

#### b) Eating disorders – Quality standard (QS175)

NICE Quality Standards reiterate the current NHSE standards for a four-week maximum timescale for children and adolescents with an eating disorder (routine cases) and this standard is to be replicated in adults and older adults with an eating disorder. Benefits of this speedier response to need include: an increase in recovery rates; a reduction in relapse rates and potential to reduce the likelihood of a need for hospitalisation. A timely intervention is also likely to increase the efficacy of the treatment provided.

In line with the need for service users to be involved with decisions around their care and the quality standard, is that psychological treatment will be discussed and tailored to the service user's needs and preferences. There may, however, be cases, such as when there is avoidant behaviour that can be associated with high-risk anorexia nervosa, when this is not the optimum course of action and a range of therapies need to be provided to address an individual's holistic needs.

Co-ordinated care is key, particularly when there is more than one service supporting a person with an eating disorder. In such cases the service user's care plan will highlight how the services will work together and detail the liaison meetings involving all services.

Transitions are highlighted as an area of risk for people with eating disorders. These transitions include moving from children to adult services, in-patient to out-patient, geographical transitions and moving between primary and secondary care. It is essential that transitions are managed well and supported, with protocols in place, to ensure that there is sufficient overlap for the service user to feel comfortable and to not feel as if they are restarting treatment and having to tell their story over again.

#### 1.4. Resource and standards - differences between adults and CYP

The introduction of nationally driven 'standards', in the form of waiting times for accessing treatment, for children and young people (those aged under 19) in 2015 led to improvement in the availability of services for children and young people. The

same did not apply for adult services and is only coming into effect through the Long Term Plan, during 2022/23.

Before the NHS Long Term Plan, the targeted investment in eating disorder services for those aged under 19, was generating a gap in the level of provision between those aged under and those over 19 years. While Norfolk and Waveney did have a dedicated adult specialist eating disorder service, and investment was happening, it was not at a level to enable the same level of support and treatment as CYP. Adult services had approximately one third the number of staff of the services for children and young people prior to the NHS Long Term Plan impacting on adult transformation

#### 1.5. Ignoring the Alarms & associated follow-up reports

The Parliamentary and Health Service Ombudsman's report ['Ignoring the Alarms: How the NHS Eating Disorder Services are Failing Patients'](#) provides key recommendations for improvement to Eating Disorder provision. These recommendations were also touched on by the [Prevention of Future Deaths regulation 28 of 2021](#). In summary, these reports identified the following opportunities to improve provision of care for people with an eating disorder:

- Eating disorders training for physicians and medical staff should be scoped and ensured to be adequate.
- The continuing and serious countrywide shortage of eating disorder specialists should be addressed through innovation and workforce planning.
- Medical monitoring provision lacked formal commissioning arrangements in most areas and must be improved.
- The Department of Health and NHS England / Improvement should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services, and undertake benchmarking of services. This was identified as supporting the challenging and high-risk times of transition between services.
- Coordination of care between services must be addressed through NICE (see NICE Quality Standard identified in section 1.3) and education
- Improvements in the robustness and reliability of data regarding the prevalence of eating disorders must be made to enable appropriate service planning and provision.
- Concern that the impact of the COVID-19 pandemic will significantly exacerbate the concerns noted.
- There must be improved oversight and frameworks for learning from serious incidents.

#### 1.6. Provider Collaboratives

NHS led Provider Collaboratives for specialist inpatient care will redesign the pathways to specialist inpatient treatment, including Adult Eating Disorders and

Children's and Young Peoples inpatient care. The overall focus is to rebalance care to focus upon community-based services in order to give wider access to care, sooner and in a more convenient location.

The establishment of NHS-led Provider Collaboratives represents a shift in the approach to commissioning of specialised mental health services, such as the eating disorders in-patient service. The Collaboratives include providers from a range of backgrounds, including voluntary sector, NHS trusts and independent sector providers who have agreed to work together to improve the care pathway for their local population. They are also expected to work closely with established partnerships within local Integrated Care System partnerships which includes local government. Each Collaborative is led by an NHS service provider which takes responsibility for the budget and commissioning the service pathway for their given population. The Lead Provider remains accountable to NHS England and NHS Improvement for the commissioning of high-quality, specialised services.

The key principles which underpin the Provider Collaborative model are:

- Collaboration between Providers across local systems
- Experts by Experience and clinicians leading improvements in care pathways
- Managing resources across the collaborative to invest in community services, alternative to admission and reduce inappropriate admissions/care away from home
- Working with local stakeholders
- Improvements in quality, patient experience and outcomes driving change
- Advancing equality for the local population

### **East of England Children's & Young People's Provider Collaborative**

Lead organisation: Hertfordshire Partnership University NHS Foundation Trust.  
Commissioners of children and young people's mental health in-patient services (including specialised services for eating disorders).

### **East of England Adult Eating Disorder Provider Collaborative**

Lead organisation: Cambridgeshire and Peterborough NHS Foundation Trust  
Commissioners of adult eating disorder services (in-patient)

### **East of England Adult Secure Provider Collaborative (East of England)**

Lead organisation: Essex Partnership University NHS Foundation Trust  
Commissioners of adult low and medium secure services (in-patient)

The three provider collaboratives are managed collectively as the **East of England Provider Collaborative**, overseen by a Board comprised of non-executive directors and Chief Executives of the partner provider Trusts. They receive commissioning support from the collaborative's Transformation and Commissioning Team (TACT), which is hosted by Cambridge and Peterborough NHS Foundation Trust.

## 1.7.Demand & Covid19 pandemic impact

The Norfolk and Waveney population has seen an increasing demand for eating disorder services over recent years. The COVID-19 pandemic had a huge impact on people's mental health including new eating disorders emerging and existing disorders exacerbating. This trend has been reflected in regional and national reporting. Other contributing factors exacerbated by the pandemic included domestic violence, relationship difficulties and financial and employment issues which in turn resulted in or exacerbated eating disorder presentations. In some cases these additional pressures resulted in opportunities for people to come forward to reach out for help as new access to support became available because of the pandemic and society's community response.

Eating disorder referrals across all providers for Norfolk and Waveney initially reduced following the start of the pandemic before rising to around double the level of referrals pre-Covid in October 2020. Since October 2020 the referral levels have consistently remained significantly in excess of the pre-Covid peaks. This significant change in referrals may have been impacted upon by people with eating disorders initially avoiding the primary care as requested as part of the Covid response and then doing so in greater numbers as restrictions lessened. In addition, schools were closed for a sustained period of time, and this may have resulted in new presentations in addition to fewer cases being recognised. The impact of the Covid lockdown may also have been a significant factor in exacerbation of eating disorders, possibly as a result of loss of support networks, increased pressure resulting from an inability to maintain routines and an increase in the use of social media where individuals may encounter unhelpful images of 'perfection' or upsetting social images and messages.

The numbers of assessments undertaken by all eating disorder providers for Norfolk and Waveney increased from November 2020 and has settled at a level between 20% and 40% higher than before March 2020. The additional number of referrals, and potentially other capacity impacts of Covid, have resulted in a detrimental effect upon waiting times for community eating disorder services across all age groups - this has been most apparent since July 2021 for adults and October 2020 for children and young people. Furthermore, acuity of need increased dramatically for children and young people with eating disorders, with the level of urgent referrals requiring an immediate response quadrupling compared to pre-Covid levels

In order to address the increase in prevalence and the underlying causes of this increase, the system has already taken several actions including:

- Expansion of specialist community team staffing, to increase capacity
- Additional funding to VCSE provider to support increase in demand
- Development of alternatives to admission - to provide more support to people with an eating disorder in the community
- Further training for specialist and broader system workforce

- Commissioning of specialist eating disorder staff on acute paediatric wards
- Increase in parent / carer support and recruitment of peer support workers

## 1.8. National Position

National and global data on prevalence of Eating Disorders:-

Estimates suggest that over 700,000 people in the UK have an eating disorder, 90% of whom are female. This is likely an underestimate as many cases do not present to health services. Eating disorders can develop at any age but risk of onset is highest for adolescents and young adults. Atypical eating disorders are the most common, followed by binge eating disorders, and bulimia nervosa. Anorexia nervosa is the least common.

A systematic review including 94 studies (time period 2000-2018) looking at the prevalence of eating disorders globally found the weighted mean of:

- Lifetime eating disorders to be 8.4% for women and 2.2% for men.
- The percentage of people at any one point in time living with an eating disorder is: 4.6% in America; 2.2% in Europe; and 3.5% in Asia<sup>2</sup>.

National and Regional Road Map to transform community Eating Disorder Services:-

NHS England & Improvement guidance on improving community-based care for adults & older adults with eating disorders stipulates that transformed community eating disorder services should:

- Ensure timely direct access for all levels of need, by maximising access and minimising waits to improve patient care, and facilitating self-referral and carer-referral (i.e. offering direct access to expert advice);
- Meet NICE guidance and pathways;
- Embed an early intervention model within their overall adult & older adult community eating disorder model i.e. the First Episode Rapid Early Intervention for Eating Disorders (FREED) model for young adults aged 18-25 year olds; (16 – 25 for all age services);
- Provide consultation and support, supervision and training to primary care and generic community mental health services;
- Embed experts by experience in service development and delivery;
- In addition to priority areas covered in section 1.2

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<sup>2</sup> Galmiche M, Déchelotte P, Lambert G, Tavoracci MP (2019) Prevalence of eating disorders over the 2000-2018 period: a systematic literature review. *Am J Clin Nutr.* **109**(5), 1402-1413.

## 1.9. Norfolk & Waveney

### a) Current services

Norfolk & Waveney CCG commissions three organisations to provide specialist eating disorder services across Norfolk and Waveney, with a total spend of £5.2m. Primary care (GP's) are commissioned to monitor physical health of people working with the specialist teams and other services will also support people with eating disorders e.g. acute hospitals. Due to historical arrangements of five separate commissioning areas in Norfolk & Waveney, there are still some inconsistencies in service provision and delivery across Norfolk & Waveney, which we are working to address. Figure 1 gives a view of the specialist services available in Norfolk and Waveney.

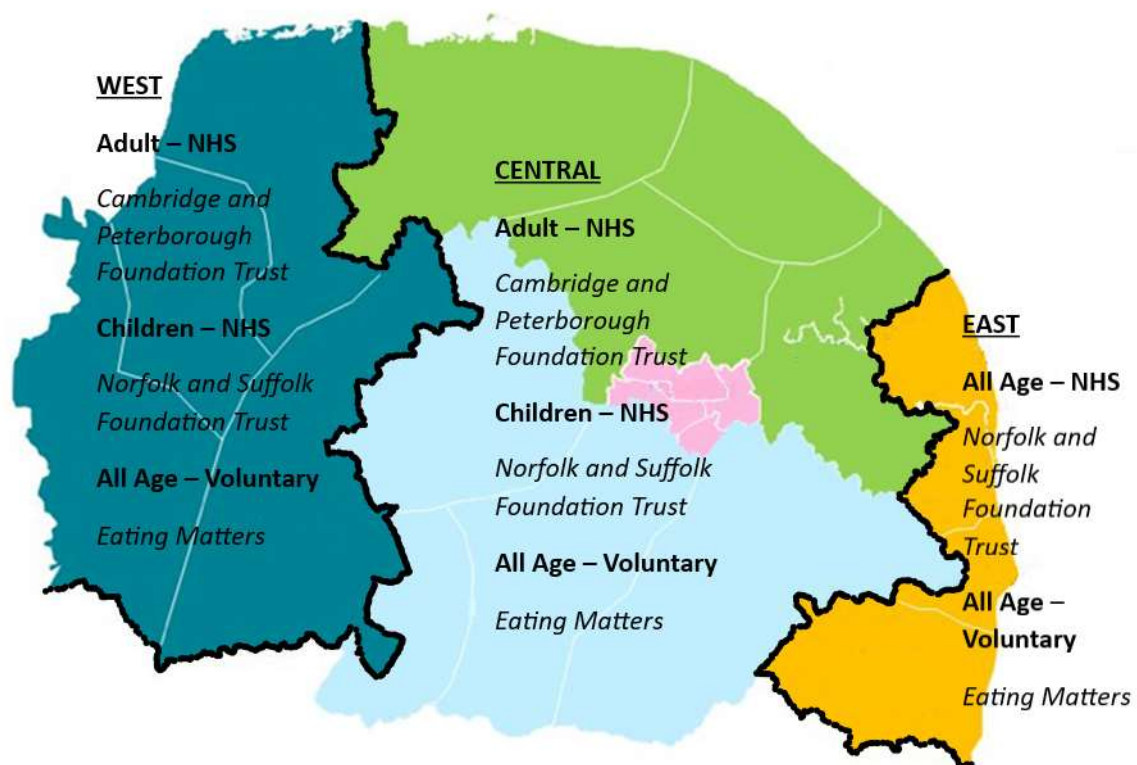


Figure 1 - Specialist Services in Norfolk and Waveney

Provider	Adults	All Age	CYP
<b>Cambridgeshire &amp; Peterborough Foundation Trust (CPFT) – Specialist ED Team</b>	West Central		
<b>Norfolk &amp; Suffolk Foundation Trust (NSFT) - Specialist ED Team</b>		East	West Central
<b>Eating Matters – Voluntary Organisation</b>	East Central West		

The Norfolk and Waveney system monitors a number of different metrics to analyse and understand the demand, capacity and profile of need in services and performance against national and local standards. There is a range of data from different providers and it is important that we consider data from the whole system i.e. not only data from the Eating Disorder services. For example, eating disorder activity data is collected on hospital admissions, specialist inpatient admissions and primary care to build a picture of how the pathway is functioning and how needs are being met both within and outside of Norfolk and Waveney. The following sections of children and young people (CYP) and adults provide a key overview of the activity in specialist services.

## **CYP Services**

There are two dedicated CYP community eating disorder teams in Norfolk, one in the west and one covering central Norfolk. The team in the East is all age. The teams provide a specialist community eating disorder service, with intensive support for higher risk CYP to avoid admission where possible. The teams currently accept referrals from GPs.

Eating Matters (a local voluntary provider) supports circa 250 CYP a year with mild to moderate eating disorders, but this provision is not formally commissioned as at 2021/22.

## **CYP resources**

In 20/21 Norfolk & Waveney CCG supported an increase in capacity within the CYP-ED teams. This increased funding from £1.5 to £2.1m, which equated to 6.5 whole time equivalent additional staffing. Additional staffing funded centred around increasing medical, psychology and therapy capacity.

In 21/22 an additional funding of £703K was allocated to CYP eating disorders, taking the total spend to £2.8m. This additional spend is being used to start developing the service in line with this strategy to ensure high quality safe services are delivered to meet the needs of CYP and their families. This £703k is supporting:

- Development of a CYP-ED day unit as an alternative to admission
- Training of parents and staff
- Digital guided self-help provision
- Co-production
- VCSE service capacity

## Activity and Performance

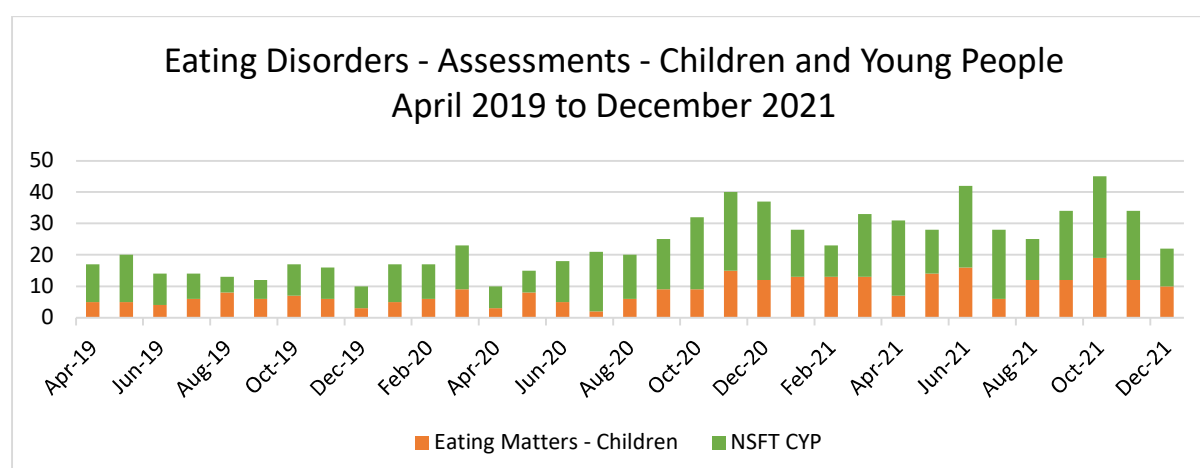


Figure 2 - Eating Disorders Assessments - Children and Young People

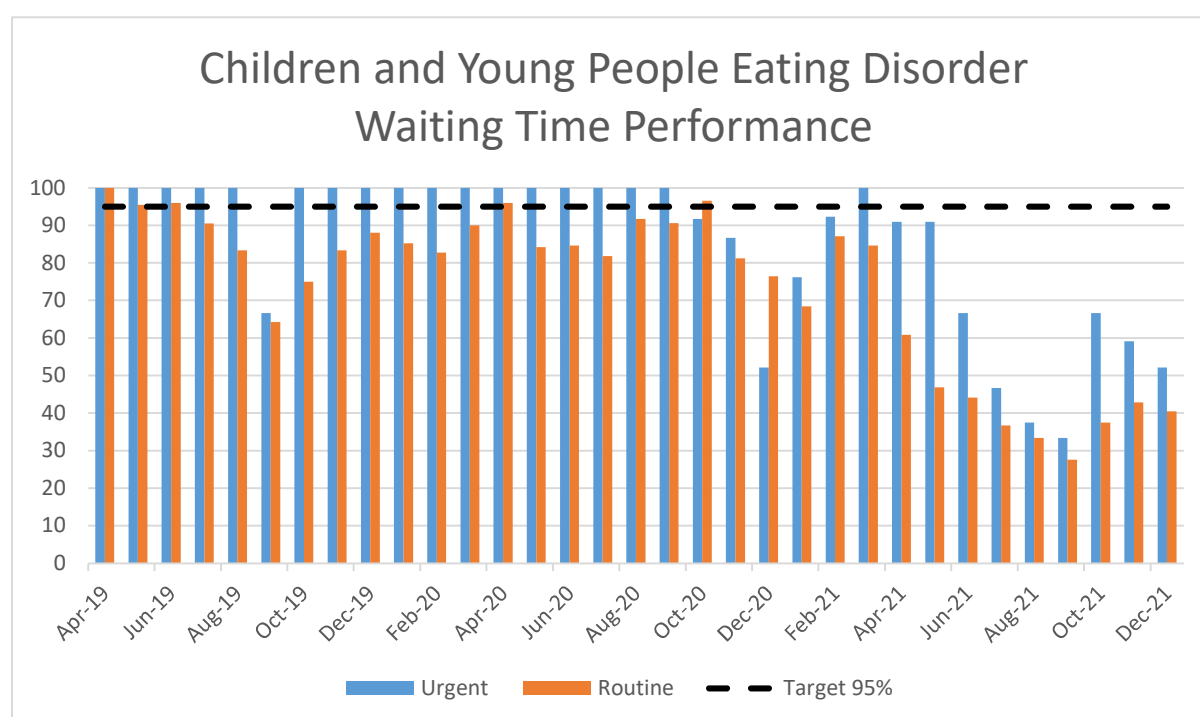


Figure 3 - Waiting Time Performance - Children and Young People

Before the pandemic, the CYP-ED community teams were performing well against the national access and waiting time standard, but due to the significant increase in referrals and acuity this was not sustained. Service delivery has been focussed on managing risk over providing therapeutic treatment, and a high number of CYP have required medical stabilisation on hospital wards and admission to specialist eating disorder services. It is not unusual to have up to ten CYP on acute paediatric wards at any one time. The problem is compounded further by the reduced number of specialist eating disorder beds available on a national level, resulting in reduced



ability to move people to the right part of their pathway at the right time. This sometime leads to individuals not receiving the level of care they should.

There are currently no alternatives to admissions available for high risk CYP with eating disorders in Norfolk and Waveney. As a result, many are being managed in the community. This resource shift can lead to those who are at lower risk waiting longer for support and treatment, resulting in escalation of need.

Despite the significant increase in funding for CYP community eating disorder services, currently £2.8m (this figure excludes the cost of admissions), a radical change is required in the service model to meet the increasing demand and acuity.

## Adult

During the 2021/22 year, adult eating disorders services – both NHS and Voluntary, Charity and Social Enterprise (VCSE) – received investment to deliver ‘core’ services, First episode and Rapid Early intervention for Eating Disorders (FREED) and to develop services to support alternatives to admission. This built on investment in 2020/21 and leads to committed recurrent spend in adult eating disorders services totalling £2.4m. Recurrent investment in eating disorder services has increased by £0.8m over the past 2 financial years. This investment has increased the number of staff in specialist community ED teams by 17.97 whole-time people, an increase of 78%.

While financial investment and transformation focus has supported increased capacity and developments of services for adults, the demand increase aligned to the Covid-19 pandemic has impacted on service delivery.

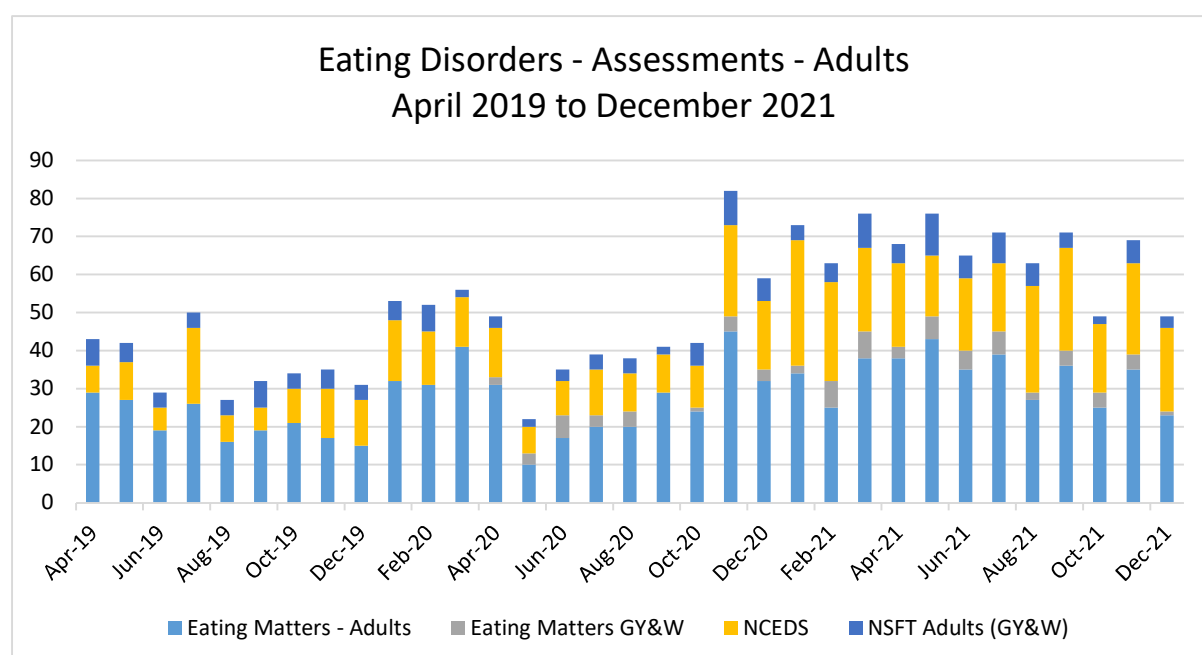


Figure 4 - Eating Disorders Assessments - Adults

As can be seen in Figure 4, the number of people that eating disorder teams are supporting at any one time – has increased by over 50% and the corresponding time that people wait for assessment is shown in Figure 5.

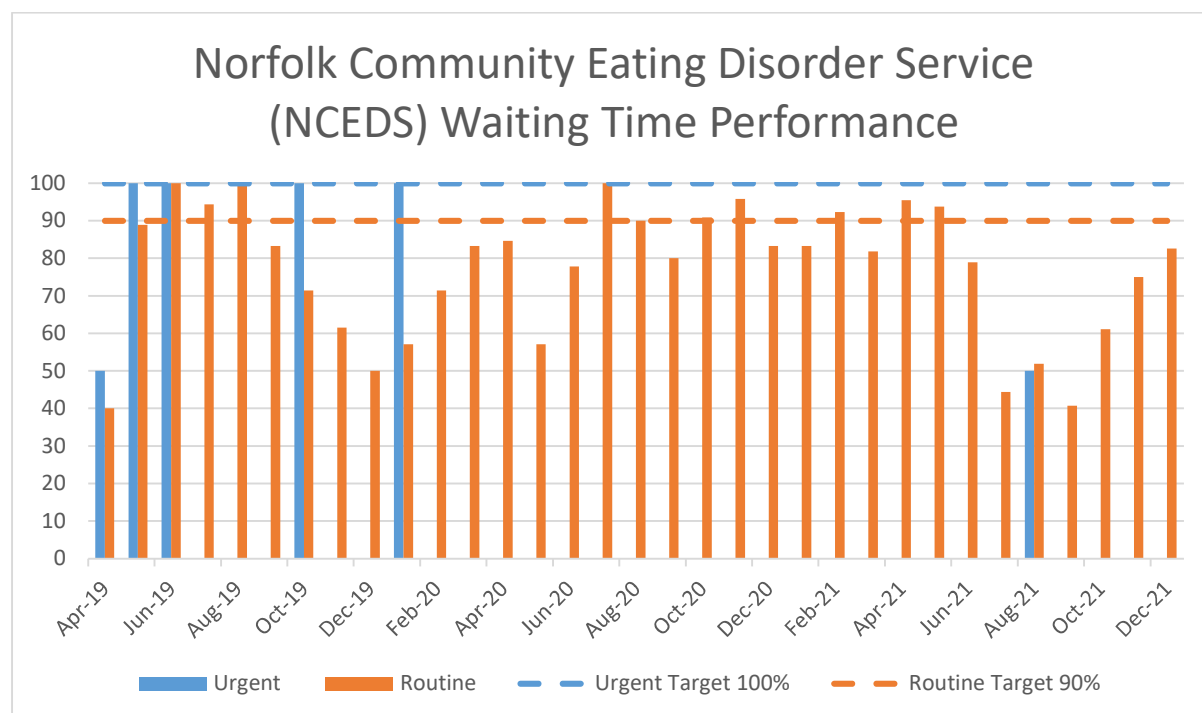


Figure 5 NCEDS Waiting Time Performance - Adults

## All-age summary

While the investment and expansion have been welcomed, we recognise areas that need particular attention to further develop and support people. This includes recognition that current services in Norfolk and Waveney were commissioned in the context of national guidance and international disease classification which has now been superseded by refreshed editions. This means that current services do not fully meet recommended provision. Critical areas:

- Prevention & early identification
- Easy access for support, advice and treatment
- Equity of service provision across Norfolk & Waveney
- Expansion of VCSE provision with clear roles and responsibilities for each service provider
- Development of a pathway to treat Avoidant Restrictive Food Intake Disorder (ARFID) – identified in versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) since current services were established and with rising demand for support
- Disordered Eating and complexity of needs
- Development of alternatives to admissions including Day Units and Home Treatment Teams to provide intensive support in the community

- Medical Monitoring – to align closer to the 2019 NHSE/I guidance and address the needs of those with disordered eating
- System-wide awareness raising and upskilling
- Increased support for parent / carers
- Increased use of digital innovations to support guided self-help where appropriate

## b) Incidence & Prevalence

The table below shows the available information regarding prevalence of eating disorders which demonstrates that in line with predicted population growth in Norfolk and Waveney the prevalence will increase over the next ten years. However, this information is based upon data that is historic and also entirely free of any of the effects of Covid 19 upon the increase of eating disorders. This is in part as a result of the Adult Psychiatric Morbidity Survey (APMS) only gathering data on eating disorders in the 2007 survey and not subsequently.

The current assumptions from NHS England and from Eating Disorders Advisory bodies is that there is no expectation of any decline from the levels of demand for services seen during the period of the pandemic. Whilst there is no up to date evidence base, giving detailed expected numbers, there is nothing to suggest that any expansion of eating disorders services will result in a situation where they are over-resourced.

**2019 Prevalence of Eating disorders in Norfolk and Waveney and predicted future prevalence based upon predicted population growth**

	Age	2019			2026			2031		
		Female	Male	All	Female	Male	All	Female	Male	All
<b>Anorexia</b>	<b>11 - 24</b>	398	136	534	410	142	552	411	143	554
	<b>35+</b>	265	92	357	285	98	383	297	102	399
	<b>Total</b>	<b>663</b>	<b>228</b>	<b>1</b>	<b>695</b>	<b>240</b>	<b>935</b>	<b>708</b>	<b>245</b>	<b>953</b>
<b>Bulimia</b>	<b>11 - 34</b>	1328	450	1778	1368	470	1838	1371	473	1844
	<b>35 - 44</b>	586	185	771	660	205	865	667	210	877
	<b>45 - 59</b>	1107	345	1452	1054	324	1378	1036	316	1352
	<b>60+</b>	443	135	578	503	155	658	544	168	712
	<b>Total</b>	<b>3464</b>	<b>1115</b>	<b>4579</b>	<b>1154</b>	<b>3618</b>	<b>4772</b>	<b>3618</b>	<b>1167</b>	<b>4785</b>
<b>Other Eating Disorders Not Otherwise Specified (OSFED)*</b>	<b>11 - 24</b>	3147	1078	4225	3241	1124	4365	3249	1133	4382
	<b>25 - 29</b>	768	265	1033	738	256	994	715	250	965
	<b>30 - 34</b>	640	205	845	632	211	843	603	203	806
	<b>35 - 44</b>	1205	386	1591	1358	428	1786	1371	438	1809
	<b>45 - 59</b>	3100	984	4084	2951	926	3877	2902	902	3804
	<b>60+</b>	2675	777	3452	3037	894	3931	3287	969	4256
	<b>Total</b>	<b>11535</b>	<b>3695</b>	<b>15230</b>	<b>11957</b>	<b>3839</b>	<b>15796</b>	<b>12127</b>	<b>3895</b>	<b>16022</b>

\*It should be noted that the data was based upon DSM-4 criteria rather than the DSM-5 criteria which would have substituted Eating Disorders Not Otherwise Specified (EDNOS) with Binge Eating Disorder and Other Specified Feeding or Eating Disorder (OSFED)

Currently the national expectation is that the levels of demand seen through Covid, will not drop. Therefore, service planning will need to incorporate a higher level of presentations than seen in the table above.

The system will continue to monitor trends in local services to determine the level of provision required meets the anticipated need. Additional work will be needed to further our understanding of prevalence within certain communities to assist targeted interventions and address potential inequalities. Prevalence is also determined by presentations which may under-represent as a consequence of treatment willingness or perception of available help. Self-presentation may also be determined by confidence in the support being offered which must be as much as possible community based and inclusive to groups who have historically been under served.

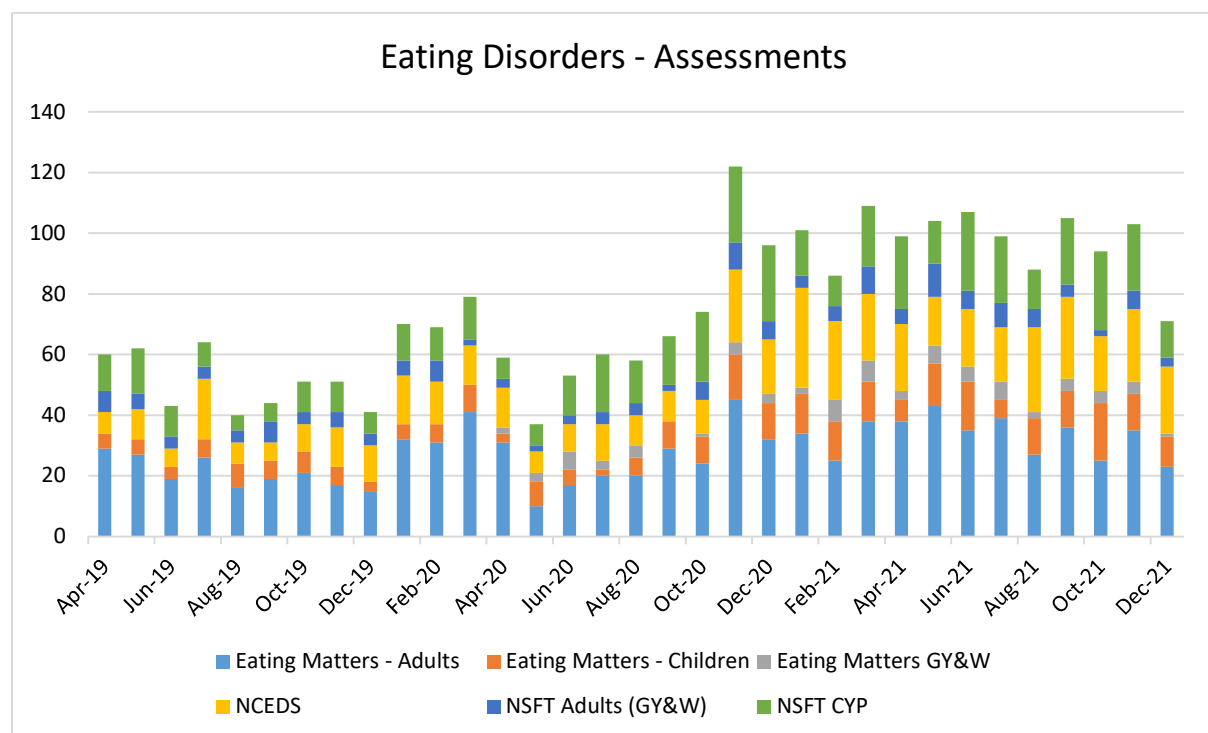


Figure 6 - Eating Disorders Assessments – All-Age

## **Section 2 – Development of a strategy**

### **2.1. A strategic approach**

This strategy embraces a collaborative and integrated approach to meeting the needs of people with an eating disorder. It considers eating disorders as part of a broader sociocultural context which can play an important part in the protective and risk factors for this range of illnesses.

The strategy will include those with disordered eating as part of a whole-population approach (the term ‘disordered eating’ is defined in Appendix 1). While this is a strategy for eating disorders, the challenges in recognising and meeting the needs of people with disordered eating must be addressed and will need to draw on the expertise of specialists in the field of eating disorders.

This strategy seeks to:

- Address current urgent needs of the population and the workforce
- Re-focus, over time, activities from the critical and intensive support often required currently, to activities which focus on prevention and earlier intervention.
- Support the whole system to recognise and meet the needs of people with a suspected or diagnosed eating disorder, and disordered eating.

This will support a larger number of people earlier in the illness, disrupt progression and minimise the impact of the illness for all affected by it.

### **2.2. Ambition & outcomes of the strategy – demonstrating an impact**

The outcomes that people experience are central to the way we gauge success and direct future improvements. These should be the combined measure of the impact of this strategy and the services associated with it.

While there is a continuing need to work with the eating disorder service specific access and waiting time standard(s) that apply nationally or locally, as a system we should measure success for an individual by the outcomes each individual achieves – directed by an approach to care and support which is driven by individual needs. Therefore, the work we have done through this strategy development is drawn into Figure 7 below, showing the desired outcomes and the corresponding metrics to assess success.

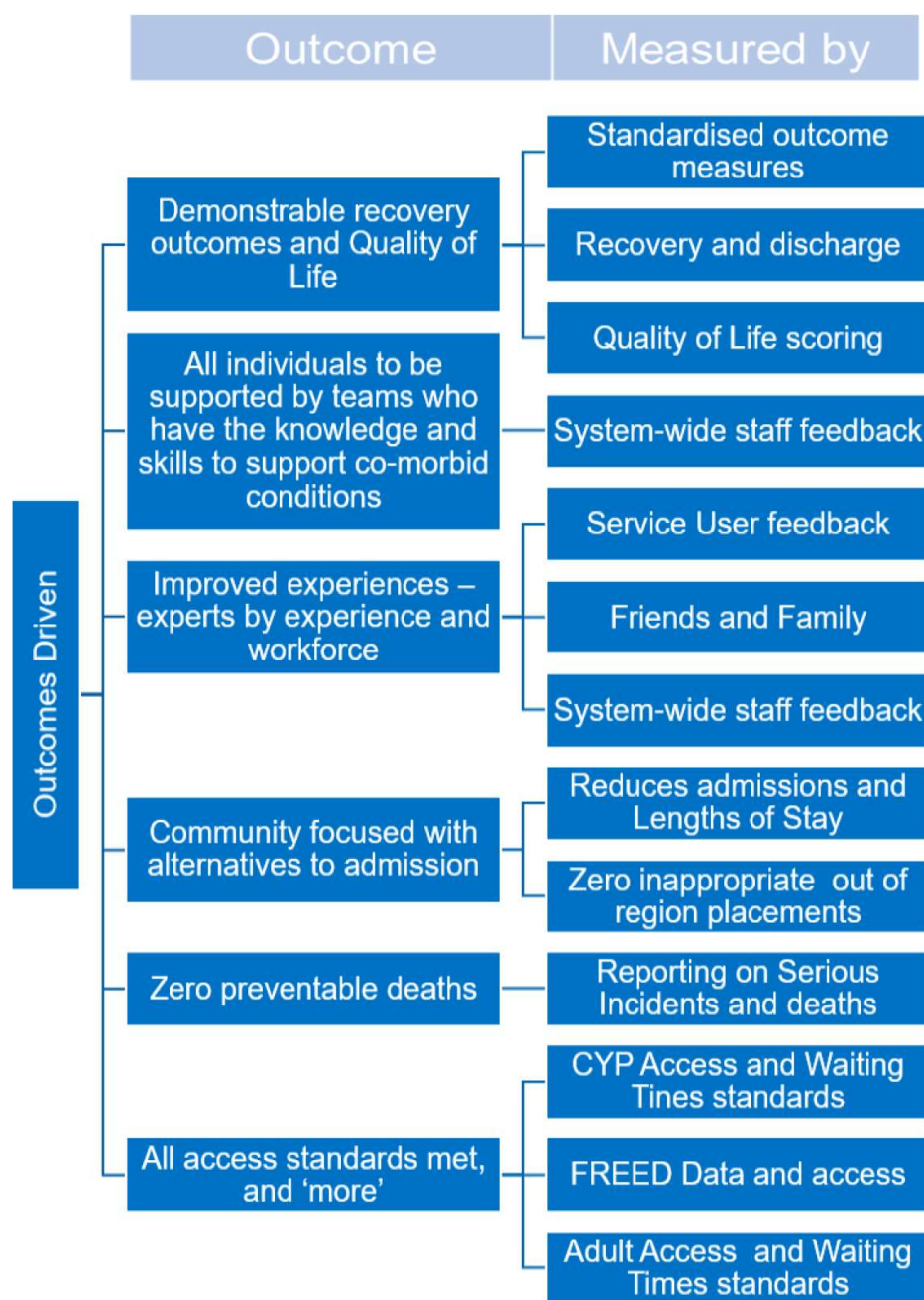


Figure 7 - System Outcomes

### 2.3. Engagement with experts – experts by experience, clinical and system partners

Since the end of 2020 Norfolk and Waveney CCG has led a group of clinical, policy and system experts to review and build plans for future system development through the Norfolk and Waveney All-age Eating Disorder Strategic and Local Clinical

Leadership Group. This group has included partners from: specialist and VCSE community eating disorder services; mental health services; acute hospitals; GP's and community providers; regional NHSE/I leaders for eating disorders; Provider Collaboratives.

A range of 'listening events' were held to give specific groups the opportunity to collectively provide input on specific areas of services for people with eating disorders. These events occurred between February and April of 2021 with groups of stakeholders encompassing Norfolk and Suffolk Foundation Trust Eating Disorders, Cambridge and Peterborough Foundation Trust – Norfolk Eating Disorders, Eating Matters, Norfolk and Waveney Acute Hospitals (Norfolk and Norwich University Hospital, James Paget University Hospital and Queen Elizabeth Hospital – Kings Lynn) and the Provider Collaborative.

Feedback from these listening events included the need to:

- Develop joint clinical working including for disordered eating
- Offer a single point of access
- Increase awareness skills for the broader system
- Remove thresholds (age and weight) for accessing and transitioning between
- Ensure availability of parent / carer support and networks
- Provide for those with Avoidant / Restrictive Food Intake Disorder (ARFID)
- Enable self-referral
- Ensure care plans are bespoke

In November 2021, our co-production partners, Rethink Mental Illness, including experts by experience provided feedback about eating disorders provision.

Feedback from these listening events included that:

- Service users should have access to their own care record
- More clinicians were required
- Step down support should be available for service users leaving in-patient services

Between 2<sup>nd</sup> February and 30<sup>th</sup> March 2022, a public survey, hosted by Rethink Mental Illness, sought feedback about eating disorder provision within Norfolk and Waveney.

As at 4<sup>th</sup> March 2022, this resulted in responses from 21 people of whom 17 had personally experienced living with an eating disorder.

Feedback from this public survey included that:

- Therapy had been beneficial
- Eating Matters had been useful
- Getting help from GPs had been difficult

- Getting referrals for support had been problematic
- Weight thresholds were not positive
- Parent / carer groups were helpful
- More training was required about eating disorders
- An ARFID pathway was required
- Food advertising and messages about health eating in schools had had a negative impact upon people's eating disorders

Further responses from people answering the survey were used to produce 'word-clouds' showing how eating disorders were currently seen and how 'ideal' eating disorders services would be described. These are shown in figures 8 and 9.

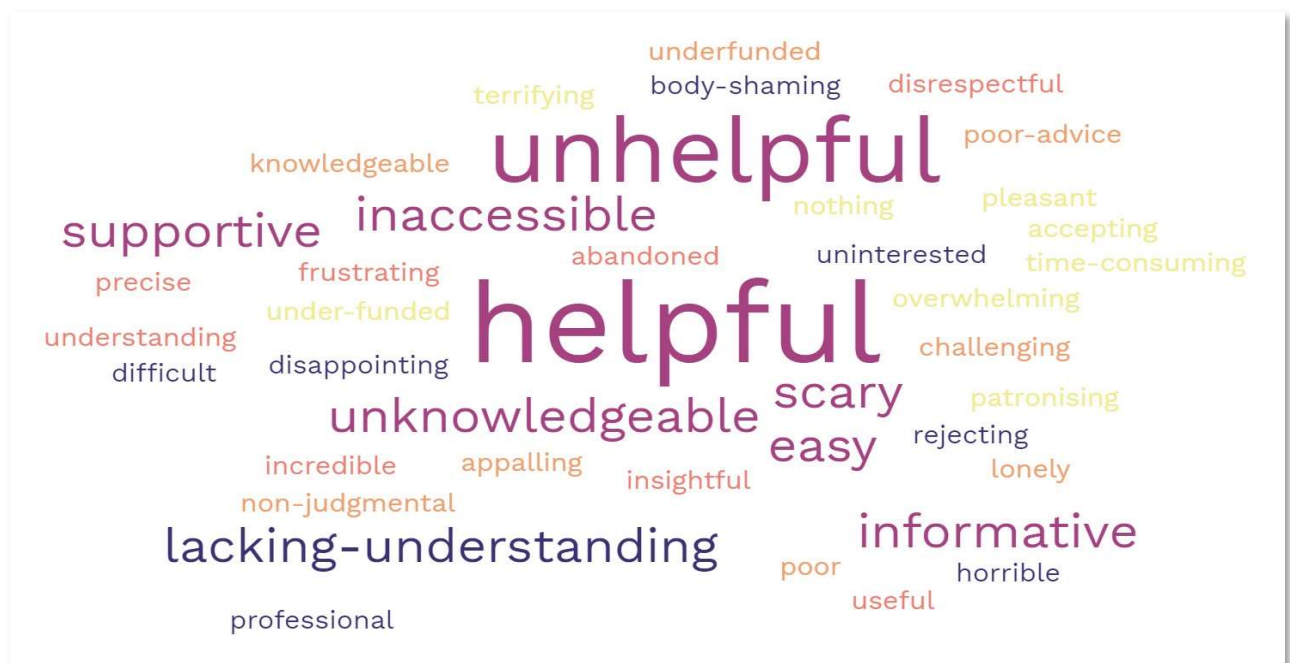


Figure 8 - How services are currently seen





Figure 9 - How people see ideal services

## Section 3 – Our ambitions for eating disorders provision in Norfolk and Waveney

### Strategic Pillars

Through work which began in late 2020, involving a wide group of clinical, operational and strategic leaders from across Norfolk and Waveney and the East of England Region we have developed the following framework for our strategy – see Figure 10. The following framework for our strategy is detailed in the four pillars below.

Pillar	Objectives
1. Preventing and reducing prevalence	<ul style="list-style-type: none"> <li>• Developing a prevention action plan</li> <li>• Awareness raising and public health – incl social media and healthy eating campaigns</li> </ul>
2. Early identification and early response	<ul style="list-style-type: none"> <li>• Eating disorders will be identified earlier by professionals, families and communities</li> <li>• We will have a clear and single easy access route for all suspected eating disorders, including self-referral</li> <li>• Advice and guidance</li> <li>• All services will meet national access standards with a long-term vision to align adult access standards with the CYP access and waiting times</li> <li>• The eating disorder pathway will assess and support all eating disorder presentations according to need</li> </ul>
3. Targeted treatment from dedicated and integrated services	<ul style="list-style-type: none"> <li>• Ensuring equitable access to person centred treatment</li> <li>• Care and treatment centred on holistic, individual goals and quality of life.</li> <li>• We will provide consistent services and information</li> <li>• Our service provision will focus on community-based care and treatment</li> <li>• Monitoring impact will be central to quality services</li> <li>• Parent, carer and family support</li> <li>• Ability to respond to and manage disordered eating, comorbid presentations and complexity as a system</li> <li>• Alternatives to admission will be our preferred approach to managing increased need.</li> </ul>
4. Strong foundations	<ul style="list-style-type: none"> <li>• System wide ownership and integrated working</li> <li>• Coproduced service developments</li> <li>• Led by system intelligence and data to drive improvements</li> </ul>

Figure 10 - Strategic Pillars

The actions to achieve each of the objectives in each pillar are set out in the following four sections.

## **1. Strategic Pillar 1 – Prevention & reducing prevalence**

The evidence base for eating disorders has developed significantly over recent years, however there is still much to learn about their development and how best to prevent them. What we do know is that prevention activities should be focussed in two key areas: fostering protective factors at the community level and with at-risk groups; and raising awareness to demystify and destigmatise eating disorders and support early access.

Prevention efforts at the community level to create supportive environments and address social and cultural factors affecting attitudes to food, physical activity and body image can influence the health and wellbeing of the whole population. By investing in a prevention focus, we will build opportunities to embed and leverage strategies to prevent eating disorders within broader efforts such as mental health promotion and obesity prevention.

### **1.1. Developing a prevention action plan**

#### **Objective:**

We will develop a plan for increasing the prevention opportunities for eating disorders.

#### **Action:**

i.	We will work with Public Health, regionally and nationally, to review current healthy living and health promotion campaigns and to eliminate or minimise potential unintended consequences.	April – September 2022
ii.	We will work with public health, regionally and nationally, to generate a. universal messaging to support positive body image. b. appropriate specific messaging to target those identified at risk of developing eating disorders.	October 2022 – March 2023
iii.	We will support the development of positive protective factors in our general population.	January – June 2023

## 1.2. Awareness raising and public health – including social media

### **Objective:**

We will raise the awareness of eating disorders, and their impact, in the communities of Norfolk and Waveney, and target areas of negative influence to minimise their impact.

### **Action:**

i.	We will include awareness of eating disorders in public health universal messaging and campaigns.	April – June 2022
ii.	We will make available public awareness literature to increase recognition and early identification of eating disorders for all. This will include literature for parents and carers, education institutes and workplaces, as well as individuals.	January 2022 – December 2023
iii.	We will assess the evidence behind the impact of social media on the emergence of eating disorders and generate a public campaign to mitigate.	July – December 2022

## 2. Strategic Pillar 2 – Early Identification & Early Response

Where prevention is not possible, the next priority must be identifying need early and ensuring a rapid and individualised response to that need. This is made challenging in eating disorders due to a key feature being that individuals often do not identify as having an illness at all, and due to frequent concealment behaviours.

While people may be reluctant to seek help for their eating disorder, for this group attendance at health services for eating disorder associated symptoms is common. Health professionals in community-based and primary care services, as well as more specialist health services, are critical to early identification of eating disorders. Additionally, environments where there may be at-risk groups, such as schools, sporting facilities and gyms are important settings for early identification.

To this end, increasing community awareness and enabling rapid access to services and support is critical to the long-term picture of eating disorders and to maximising the recovery and outcomes for individuals. As a key step towards this, we have established First episode Rapid Early intervention for Eating Disorders (FREED) across our adult services, with opportunity for CYP to access this pathway if appropriate to meet their need and help support engagement. There remains more we can do in this area though, outlined in the following objectives and actions. As the community transformation pathways develop new opportunities will arise to identify people with eating disorders through ongoing work around physical health

integration. it is important that we harness these encounters 'making every contact count' to better understand and support people who have issues with disordered eating.

## **2.1. Eating disorders will be identified earlier by professionals, families and communities.**

### **Objective:**

We will have a range of information available, appropriate to different audiences, to ensure everyone is able identify the signs of eating disorders early, and know what to do to access support.

### **Actions:**

i.	We will scope existing available information, its appropriateness and its efficacy.	April – June 2022
ii.	We will develop information, where it is lacking or requires review.	July – December 2022
iii.	We will work with system partners to distribute information on regular basis.	Start January – March 2023

## **2.2. We will have a clear and single easy access route for all suspected eating disorders, including self-referral**

### **Objective:**

We will establish an all-age single access point of access to services for people presenting with eating disorders, including the ability to identify and include an onward multi-disciplinary team for complex cases or disordered eating with other co-morbidities. This team would include dedicated resources and combined specialist skills to provide a route of support for people with disordered eating.

### **Actions:**

i.	We will develop a single point of accessing all community services for people with eating disorders, including those with LD and NDD, in partnership with NHS and VCSE.	Develop July – September 2022 Start January – March 2023
ii.	We will develop a single triage process with multi-disciplinary skills, including those to support individuals with LD and NDD.	Develop July – September 2022 Start January – March 2023
iii.	We will accept self-referrals.	Develop July – September 2022

	Start January – March 2023
iv. We will regularly review the demography of people accessing services to identify where there may be underrepresentation of groups who we would have expected to engage with services.	July – September 2023
v. We will develop ways of reaching out to groups who may encounter more challenges to engaging with services at the earliest possible opportunity working as a system to redress inequalities to access of care.	April – June 2023

### 2.3. Advice and guidance

Feedback from all professionals is that access to timely advice and guidance provides confidence to support the identification and management of risk and needs. People with experience of eating disorders and their carers also tell us that they need access to professional advice and support at all points through the process.

#### **Objective:**

There will be an advice and guidance line for professionals, to provide a mechanism for supporting decision making for pathways and clinical management.

There will be a help and support line for the public including those who may need to access a service themselves and those supporting someone with an eating disorder.

#### **Actions:**

i. There will be a service in place to offer routine advice and guidance, including urgent support where risk is deemed to be high.	January – March 2023
ii. There will be a service in place to provide information to guide and support the public.	April – June 2023

## **2.4. All services will meet national access standards with a long-term vision to align adult access standards with the CYP access and waiting times**

In 2015 NHS England introduced standardized national targets for CYP eating disorders services to start evidence-based treatment, concordant with the recommendations from NICE. These are:

Routine – 4 weeks referral to treatment

Urgent – 1 week referral to treatment

Emergency – 24-hour response<sup>3</sup>

Norfolk and Waveney clinical leaders assert that the standards for adults accessing treatment should be the aspiration for our population.

### **Objective:**

There will be alignment of all services to the ambitions for access and treatment set out in the CYP-ED access and waiting time standards.

Recognising this is an ambitious target but also that adult service users deserve equality of access and opportunity for full recovery, the system will work together to streamline processes and agree models of care with appropriate resources to support this.

### **Actions:**

i.	There will be a review of the capacity required to meet these access target against current activity and forecast prevalence.	July – September 2022
ii.	We will jointly explore the best way to meet needs under this access target, and resource the system to achieve this.	October – December 2022

## **2.5. The eating disorder pathway will assess and support all eating disorder presentations according to need**

Services historically have been led by diagnosis. Services moving forwards will become needs led and age appropriate - this means that services will not be driven by criteria such as age, but individuals needs will drive the clinical approach provided. The removal of age and weight thresholds as barriers to intervention is key to seamless pathways of care. Holistic approaches to care may necessitate support workers alongside other therapists to provide a needs led approach for the individual with an eating disorder.

It is important that the individual receives bespoke therapies that meet their needs at any given time independent of their weight and other mental health conditions. This

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<sup>3</sup> MaRSiPAN pathway should be followed for physical emergencies, however CEDS may contribute to assessment of psychiatric emergencies

should include and not be exclusive to, people with a diagnosis of complex emotional need, ARFID and dual diagnosis. These therapies can be offered in tandem if appropriate and beneficial to the individuals recovery journey. This would necessitate a collaborate approach to therapy with health professionals engaging in clinical conversations and mutual learning.

**Objective:**

Access to support will be led by the needs of the individual, not thresholds, criteria or diagnosis.

People will be able to self-refer, with services working to support access from all and follow-up information to be sought and provided by appropriate partners.

**Action:**

i.	We will develop an Avoidant and Restrictive Food Intake Disorder (ARFID) service within our eating disorders pathway.	April – December 2022
ii.	We will develop the system processes and resources to manage individuals presenting with a range of needs (co-morbid presentations) e.g. physical health, mental health, or LD / neurodevelopmental disorders.	January – March 2023
iii.	We will develop a support and sustain pathway to maximise the opportunities for people to live in the community with an enduring eating disorder.	October – December 2022

### 3. Strategic Pillar 3 – Targeted treatment from dedicated and integrated services

Once identified our system must be able to respond appropriately to the needs of individuals. This requires having in place clear pathways, access to services, collaboration between system partners including primary and secondary care and VCSE (Voluntary, Community and Social Enterprise), dedicated specialist services which are able to provide evidence-based treatment, and a system which is equipped to work collaboratively and responsively. This provision should be community based wherever possible, with the options for providing support and treatment in the community to meet individuals increasing levels of need and to facilitate discharge from inpatient care when this has been clinically necessary. The system has been working to reduce delays in the pathways of care which are unhelpful and potentially harmful to individuals and frustrating for professionals. Whilst progress has been made, there is still more that we can do to improve this further.



### 3.1. Ensuring equitable access to person centred treatment

#### **Objective:**

We will ensure that individuals have access to the most appropriate treatment to meet their needs and personal goals, and NICE concordant treatment will be available for all.

All services and approaches will be accessible for all, making appropriate adaptations where needed, and treatment will be adapted to meet the needs of the individual.

#### **Actions:**

i.	Eating Disorders teams will be enabled to share specialist resources between teams e.g. very specialist clinical skills across providers, through appropriate governance structures.	January – March 2023
ii.	We will undertake a review of the skills, environments and resources to be able to meet all needs (e.g. sensory adaptations).	April – December 2022
iii.	From ii, we will integrate training needs into the workforce and investment plans, especially for ARFID patients and those with a learning disability or neurodiverse.	July 2022 – March 2023

### 3.2. Care and treatment centred on holistic, individual goals and quality of life.

We will ensure quality of life and holistic, person-centered goals are central to care and treatment planning. This is demonstrated through assessment and identification of need as part of a collaborative process between the person presenting with eating disorder and services.

#### **Objective:**

People presenting with an eating disorder will be considered an equal partner in their treatment pathway. Individuals daily living activities will be facilitated through a holistic approach to goal setting.

Services will work to enable people to tell their story once and will aim to provide continuity of care.

#### **Actions:**

i.	Every person engaging with ED services will receive a copy of their care plan once agreed between all partners, aiming for digital integration.	January – March 2023
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ii.	Professionals in our system will be enabled to share appropriate clinical information easily, ideally through interoperability of clinical systems.	January – March 2023
iii.	We will introduce a route for more effective communication between services, for example hospital passports for those with ED.	April – June 2023
iv.	We will introduce a method which enables people to identify and monitor their own goals – for example the current system development of Dialog+ and an appropriate CYP option.	April – June 2023
v.	We will review the skills and professional mix in our ED teams so that they can meet new and emerging presentations e.g. Sensory components of ARFID.	January – March 2023
vi.	We will ensure the workforce is enabled to meet needs that address this objective.	April – June 2023

### 3.3. We will provide consistent services and information

#### **Objective:**

Information will be clear and available to people presenting with eating disorders to outline expectations of the services.

There will be clear, open and consistent expectations of the individual presenting with an eating disorder working towards their goals.

All eating disorder services will offer comparable services.

#### **Actions:**

i.	We will develop a single set of information, in a range of accessible formats, across providers, to inform individuals presenting with eating disorders.	January – March 2023
ii.	We will develop a set of principles for all eating disorders services in Norfolk and Waveney, including - a) All professionals commit to person centred care-planning. b) Maintaining continuity of treatment where clinically appropriate e.g. driven by need, respecting wishes and not constrained by criteria.	April 2022 – March 2023
iii.	We will review our existing arrangements and processes for managing transitions between services against national guidance, best practice and learning to ensure these are approached and managed robustly.	April – June 2022

### 3.4. Our service provision will focus on community based care and treatment

Evidence suggests that outcomes for individuals with an eating disorder are far better if treated in the community and close to home. Guidance from leading national bodies<sup>4</sup> recommends inpatient treatment should only be pursued when the level of physical or psychiatric risk cannot be managed safely in the community.

We know from working with the Provider Collaboratives that the level of specialist ED inpatient activity for adults from Norfolk and Waveney has historically been higher than the regional average. For CYP there was also a spike of these specialist admissions through the Covid-19 pandemic.

Therefore, in Norfolk and Waveney we want to drive forwards the increased capacity and capability of services across the system to be able to support this.

#### **Objective:**

Support and treatment will be available at all stages of need, from early intervention to support and sustain, and delivered in the community wherever possible.

We will maximise opportunities for step-up and step-down support, expanding on current plans for alternatives to admission in order to maximise recovery and reduce (relapse) chronic and recurring eating disorder symptoms.

#### **Actions:**

i.	We will continually scope opportunities for innovative / additional community provisions, learning from best practice and innovations such as digital technologies (e.g. Attend Anywhere).	January – March 2023
ii.	We will provide an option for people who have been discharged from eating disorders services to rapidly re-enter services if needed, if clinically required.	July – September 2022
iii.	People engaged in eating disorder services will be supported to recover and maintain individually meaningful activities - e.g. work and training support - through working with partner agencies and a review of skills within the eating disorders teams.	January – June 2023

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<sup>4</sup> [Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care Guidance for commissioners and providers](#)

iv.	We will review current alternatives to admission services (in progress) regularly to understand impact and ensure most effective allocation of resources as needs change.	July – September 2023
v.	We will ensure people have equal access making fair and reasonable adjustments for underserved groups and people with additional needs.	April – June 2023

### 3.5. Monitoring impact will be central to quality services

#### **Objective:**

Services will utilise an agreed standard tool in partnership with individuals with eating disorders to guide the pathway of recovery and assess impact.

We will use standardised ED outcome measure with consistency across the system, to understand impact of services and inform improvements

#### **Actions:**

i.	We will work with NHSE regional group, to review current outcome measuring and monitoring against current practice and national recommendations.	April – June 2022
ii.	From ii. we will agree an approach to outcomes measures which enables system benchmarking and shared objectives.	April – June 2022

### 3.6. Parent, carer and family support

#### **Objective:**

We will consider all aspects of an individual's community to support recovery and treatment. Support for families and carers is vital to recovery and to reduce impact of the emotional impact of behaviours associated with eating disorders.

#### **Actions:**

i.	We will establish parent / carer support for all age groups	July – September 2022
ii.	We will ensure people have access to training opportunities to enable them to better support loved ones experiencing an eating disorder	July – September 2022
iii.	We will ensure that parents, carers and families of people experiencing an eating disorder have information on psychological support available to them, and information on	July – September 2022

	statutory carers assessments and other local carer support groups	
iv.	We will work with system partners to explore opportunities for respite	April – June 2023
v.	A person's wellbeing will be supported holistically, to include physical and socio-environmental support, such as accessing meaningful activities (employment / education), financial advice and social engagement. This will include strengthening links with Social Prescribing, community based rehabilitation and Individual Placement Support.	April – June 2023

### 3.7. Ability to respond to and manage disordered eating, comorbid presentations and complexity as a system

We have recognised there are people with presentations not diagnosable as an eating disorder but which nonetheless require some of the skills and knowledge of eating disorder specialists as part of system-wide multi-disciplinary care. This often involves individuals needs requiring the care and treatment from teams other than the eating disorder specialists, and with the consultation or distanced input from the eating disorder specialist.

Recent years have identified key groups in our population whose needs require a focussed attention in our services such as those with ADD, NDD, LD, and other mental health conditions. This requires awareness in eating disorder teams of a range of other mental health conditions.

#### **Objective:**

Support will be provided by appropriately trained clinicians supporting the eating disorder primary need who will lead on a person's care. They will facilitate access to a range of interventions according to presenting needs from other teams avoiding thresholds and barriers to care.

Workforce across our system, outside of eating disorder teams, are able to:

- a) support people with an eating disorder who may have other comorbid needs
- b) support people with disorders of eating<sup>4</sup>

Community eating disorders services offer specialist advice and guidance – this is included in pillar 2.

#### **Actions:**

i.	We will provide eating disorder practitioners with the resources / skills / support to meet the needs of those with an eating disorder.	July – September 2022
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ii.	We will scope the needs and numbers in our system workforce, outside of eating disorders teams, for a) Awareness raising b) Supportive interactions c) Therapeutic approaches suitable for those with needs co-morbid to eating disorders d) Therapeutic approaches suitable for those with needs related to disorders of eating e) Medical monitoring & medical stabilisation	July – September 2022
iii.	We will work with NHSE Regional group and Health Education England to scope training opportunities and competency frameworks to meet ii.	July – September 2022
iv.	Teams will be enabled to make reasonable adjustments - including the uptake of specific training to support these adjustments to be made. This should include, but not exclusively, severe mental illnesses, learning disabilities, neuro-developmental disorders, autistic spectrum disorder and those. It will also consider life stages and demographics which may put people at increased risk of developing an eating disorder, such as those in the LGBTQ communities and ethnic minorities.	October – December 2022
v.	We will strengthen links and partnership working with teams that can offer skills and resources to support the holistic needs of people with eating disorders, such as ASD services, Social Care, mental health crisis teams and employment support services.	October – December 2022

### **3.8. Alternatives to admission will be our preferred approach to managing increased need.**

#### **Objective:**

All admission will have a clearly defined purpose and will be needs, not resource, led – i.e. where medically required.

If admission is a risk, planning and communication takes place with partner organisations to facilitate the highest level of care, treatment and safety

There will be a risk informed approach working across the system – positive risk taking while having appropriate risk management plans in place.

#### **Actions:**

i.	During admissions Multi-Disciplinary Teams (MDT) / Community Eating Disorders Service (CEDS) maintain contact, are involved in care planning and discharge planning.	July 2022 – June 2023
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ii.	Community based intensive support options (i.e. day services and home treatment) will be available to intensively support where escalating need is identified in community - to reduce likelihood of admission and length of stay.	April – December 2022
iii.	We will establish a system MDT with appropriate governance arrangements and escalation.	April 2022 – June 2023
iv.	We will strengthen links with community teams that support people with Learning Disability, Autism or both to ensure that CTR or CETR reviews are undertaken to provide the right level of care at the right time to prevent admission wherever admission.	April 2022 – March 2023

#### 4. Strategic Pillar 4 – Strong Foundations

We recognise the importance of the system developing the resources and skills to deliver this strategy. Linking with previous objectives which relate to system-wide training and skills development, the following objectives form strong foundations for our system to develop the response our population needs.

##### 4.1. System wide ownership and integrated working

There needs to be a wider recognition of the role all system partners have in the care and treatment of individuals with eating disorders. Integration of eating disorder interventions with other mental health pathways is vital as we seek to educate our workforce.

The system needs to be able to assure itself, as partners in the provision of care and treatment for eating disorders, that the development of services is led by clinical focus and experts by experience.

##### **Objective:**

As part of our pathway to services, we will continually take opportunities for feedback out to the wider system.

We will establish a route for clinical leaders and experts by experience to take a front seat in examining the outcomes of services and in directing the development of services moving forwards.

**Actions:**

i.	We will establish a schedule and process for ongoing feedback from our system partners and experts by experience.	April – December 2022
ii.	We will explore the appetite and routes for establishing a Norfolk and Waveney eating disorders board to provide strategic leadership and develop services as a system moving forwards.	October 2022 – April 2023
iii.	We will establish governance structures and processes for establishing the proposed board in ii).	April – June 2023

**4.2. Coproduced service developments****Objective:**

We will ensure experts by experience are equal partners and their voice and needs are embedded in all service design and developments.

**Actions:**

i.	To have experts by experience (representatives from CYP, Adults / Parent Carers) on the Norfolk and Waveney eating disorders board.	July – September 2022
ii.	To engage with experts by experience in an environment that is accessible and conducive to enable their contribution to effectively shape services.	July – September 2022
iii.	We will make use of existing individual feedback and combine this to form data which can make up a richer overview of the whole system. This will also contribute to ongoing developments.	October – December 2022

**4.3. Led by system intelligence and data to drive improvements**

Norfolk and Waveney system partners will develop an agreed consistent approach to capturing and sharing data for eating disorders. This will enable all stakeholders to have sight of robust information to drive forward system improvements.

**Objective:**

We will develop a dashboard of data which illustrates the need and how, as a system, we are able to meet the needs of people with eating disorders.

We will use research on prevalence and incidence, and population health management approaches to focus on at risk groups.



**Actions:**

i.	Review and align existing data extractions to develop a dashboard which supports ongoing system development.	October – December 2023
ii.	Regularly look at broader system metrics to develop a broader view of the impact of eating disorders on individuals and the wider system. Including primary care, acutes, SEDU, education, local authority and public health.	October – December 2023
iii.	Agree standardised outcome measures across pathways and providers.	October – December 2023
iv.	Ensure that those standardised measures are captured, reported on and flowed to the MHSDS (Mental Health Services Data Set).	October – December 2023
v.	Regularly benchmarking our activity and performance across all aspects including workforce and quality.	October – December 2023

## Summary diagram of the strategy



Figure 10 - Summary of the strategy

## What will the journey look like once the strategy is in place?

The ambitions set out in this strategy provide the basis for a new pathway into services or support for eating disorders. Figure 11 illustrates this pathway, showing a single access point for individuals needing support and treatment themselves, for those working professionally with or the parents / carers / family members of people living with an eating disorder. From the access point, it goes on to show that the system will work collaboratively to ensure the pathway flexes to the needs of individuals.

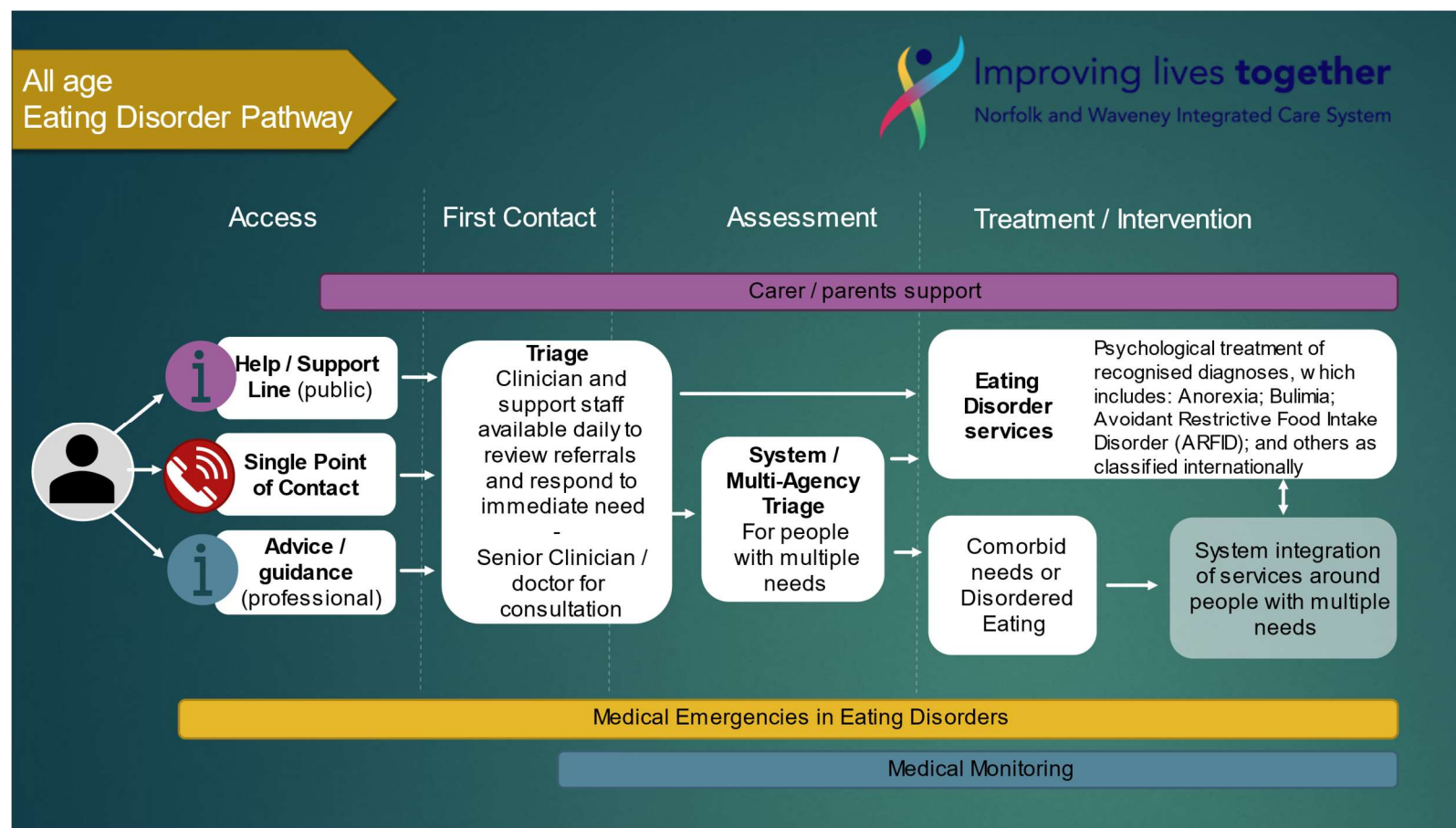


Figure 11 - All-Age Eating Disorder Pathway

### **Delivering the pathways - A whole-system approach**

The next step on our journey is to ensure that the strategy we have developed as a system is delivered as a system, in a flexible approach that can respond to new challenges as they become apparent. To do this, we are establishing a Strategy Oversight Group to take forward the ambitions and ensure they are embedded into the new integrated care system.

## Section 4 – Delivering the next steps

### 4.1. Communications and engagement

We will continue to work with system-wide stakeholders and experts by experience, to both ensure the strategy is implemented with recognition that the process will continue to evolve within the developing landscape of the Integrated Care System (ICS), and that lessons learned from the implementation will inform next steps.

Throughout the journey implanting the strategy, our successes and challenges will regularly be communicated through the ICS and through public communication channels.

Crucially, we will continue to listen to those experiencing an eating disorder and those working to support them. We will build on this ongoing partnership and incorporate feedback regularly into our planning.

### 4.2. Summary / conclusion

We have invested significantly working collaboratively with teams and system partners to improve care for those with eating disorders and their families. We have achieved considerable improvements however there is more to be done. We have significantly increased our specialist service capacity, with early intervention offers and intensive support available for those with increasing need in the community. We have established a medical monitoring provision with primary care and processes for those who are medically unwell or with complexity to be supported through our system.

However, we know there are still many areas where we need to develop the system offer further to provide comprehensive holistic care. We recognise that work needs to continue at pace to deliver best practice to meet the increasing incidence and complexity of eating disorders. This must also respond to the rising demand and acuity of all forms of disordered eating that have presented during the COVID-19 pandemic.

We have built strong foundations across the system, from which we are working with system stakeholders to develop services which will focus on prevention and early intervention and strive to be innovative and collaborative with an all-age quality improvement needs-led driven approach. This strategy is a testament to that hard work, and provides us with a roadmap for the next steps in our journey to providing the best possible care and treatment for our population.

## **Appendix 1 - Definitions**

### **Avoidant Restrictive Food Intake Disorder (ARFID)**

ARFID has been newly recognised as an eating disorder diagnosis since current services were established and is seeing rising recognition and demand for support. ARFID is when people avoid certain types of food or restrict their intake of particular food or food types. This can be for a variety of reasons including a sensitivity to texture, taste, smell or appearance of food. These can also be as a result of a distressing experience with food or a particular food type. ARFID can co-occur with anxiety disorders, autism and Attention Deficit Hyperactivity Disorder (ADHD) and it is therefore important that a multi-disciplinary approach is taken to provide support to the service user with all aspects of their treatment. As with other eating disorders, some people with ARFID have had their symptoms exacerbated by the Covid pandemic for many of the same reasons as other people with eating disorders.

To date, there has been no dedicated ARFID pathway or provision. This is noted as a priority development need in our system, and clinical partners are currently working on options for delivery

### **Complexity and disorders of eating**

Disordered eating, whilst not classified as an eating disorder in psychological terms, contains elements of commonality with eating disorders in terms of the healthcare needs for the person. People with mental health conditions such as Obsessive Compulsive Disorder (OCD), Autism Spectrum Disorder (ASD) or Personality Disorders and Complex Trauma may demonstrate behaviours which impacts upon their eating. Some people have an eating disorder, which is comorbid with another condition, for example OCD, ASD and/or Complex Trauma, who may benefit from treatment within an eating disorders service first. Other people, who primarily present with disordered eating, may benefit from consultation from the Eating Disorders Service. However an eating disorder focused therapy itself may not be helpful or may even be harmful in some cases, because it will not be focusing on the underlying psychological causes of the primary condition and therefore could result in an escalation of unhelpful coping behaviours. Levels of disordered eating have increased since the start of the COVID-19 pandemic, often as a result of people's mental health declining. For this reason, there is a need for systems to be in place to support the teams providing the treatment for the patient's primary condition with the disordered eating, for example dietetic, medical or nursing support. This support would aim to provide psychoeducation to the health professionals regarding why it would be clinically misplaced to treat the disordered eating as an eating disorder, and also how to support the patient, medically and nutritionally. The eating disorder team will have a role to play in upskilling other services thus enabling earlier intervention and support.



## Appendix 2 – Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ARFID	Avoidant / Restrictive Food Intake Disorder
ASD	Autism Spectrum Disorder
CBTE	Cognitive Behavioural Therapy – Eating Disorders
CCG	Clinical Commissioning Group
CEDS	Community Eating Disorders Service
CETR	Care, Education and Treatment Reviews
COVID-19	Coronavirus Disease 2019
CPFT	Cambridge and Peterborough Foundation Trust
CTR	Care and Treatment Reviews
CYP	Children and Young People
CYP-ED	Children and Young People – Eating Disorders
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating Disorder(s)
EDNOS	Eating Disorders Not Otherwise Specified
FREED	First Episode Rapid Early Intervention for Eating Disorders
FT	Family Therapy
GP	General Practitioner
ICD	International Classification of Disease
ICS	Integrated Care System
IPS	Individual Placement Support
LD	Learning Disability
MaRSiPAN	Management of Really Sick People with Anorexia Nervosa
MDT	Multi-Disciplinary Team(s)
N&W	Norfolk and Waveney
NCEDS	Norfolk Community Eating Disorder Service
NDD	Neurodevelopmental Disorder
NHS	National Health Service
NHSE	National Health Service England
NHSE/I	National Health Service England and Improvement
NICE	National Institute for Health and Care Excellence
NSFT	Norfolk and Suffolk Foundation Trust
OCD	Obsessive Compulsive Disorder
OSFED	Other Eating Disorders Not Otherwise Specified
PD	Personality Disorder
PFD	Prevention of Future Deaths report
PHSO	Parliamentary and Health Service Ombudsman
TACT	Transformation and Commissioning Team
VCSE	Voluntary, Community and Social Enterprise