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Ten key messages for commissioners

1. Eating disorders are severe mental illnesses with serious psychological, physical and social consequences. Anorexia nervosa (AN) has the highest mortality amongst all psychiatric disorders. People with ED commonly experience additional mental health problems, particularly depression, physical illness, difficulties in intimate relationships and the interruption of educational/occupational goals.

2. Over 1.6 million people in the UK are estimated to be directly affected by eating disorders. This is likely to be an underestimate as we know there is a huge level of unmet need in the community. These illnesses usually begin in adolescence and young adulthood with a worrying trend towards younger children developing ED. Onset at this critical time in a young person’s life can have a devastating effect on normal development with a restriction of opportunities that can extend into adult life. The development of personal autonomy and independence can also be affected, which can have an impact on meaningful engagement with treatment and outcome.

3. Transitions between different services are the norm for patients with ED: primary, secondary and tertiary care; medical and mental health services; child and adolescent services and adult services; family home and student abode. Robust transitional policies must be developed and training needs met to avoid the associated risks to patients.

4. The burden of ED on carers is very high. People with ED are often ambivalent about treatment even in the face of severe illness. This places carers in a position of battling against their loved one whilst worrying that they are to blame. Caring for someone with an ED carries a high emotional and economic cost. Carers of anorexic patients have reported similar experiences in terms of the difficulties experienced to those of carers of adults with psychosis and higher levels of psychological distress.

5. There is a critical window for intervention for people with ED. AN does not improve spontaneously and the prognosis for all ED worsens with time. Recovery is less likely if an ED has remained untreated for more than 3-5 years. Early identification and intervention with access to effective stepped care pathways is of paramount importance to improve clinical outcome and increase cost-effectiveness.

6. Good quality comprehensive services for people with ED are not yet available in many parts of England. The majority of people with ED are therefore managed in non-specialist settings where treatment is very variable. Access to specialist treatment for all people with an ED in England should be a priority in the new commissioning landscape.

7. New commissioning arrangements have the potential to disrupt a patient’s treatment because community services and more intensive services (daycare and inpatient) are commissioned separately. Ensuring clinical and cost-effectiveness, particularly for those with severe ED, requires access to both community and residential components in a flexible way, unhampered by funding streams.

8. Health care costs for ED in England have been estimated as £80-100m with overall economic cost likely to be more than £1.26bn per year. This highlights the importance of optimising service provision for this group of patients. Effective and well-managed care pathways will be critical to this.

9. Stigma related to ED has far-reaching effects. Misunderstanding of these illnesses influences (a) people who are deterred from asking for help and support through fear of being judged, (b) carers who often feel blamed, (c) health professionals in their treatment decision-making, and (d) the health service and commissioners through lack of structural investment in ED services.

10. Further research is necessary to develop optimal interventions and care pathways for people with ED. Severe and enduring or ‘treatment resistant’ cases present the highest cost (per patient). Evidence for the most effective management of these cases is sparse. In order to improve overall outcomes and cost-effectiveness, and particularly for this high cost group, ongoing investment in clinical services for research, development and innovation is a must.

As part of this, a priority for commissioners of comprehensive ED services must be to commission integrated care pathways that support flexible and seamless patient care. NHS England and Clinical Commissioning Groups should have a commitment to work together to ensure this.
The Joint Commissioning Panel for Mental Health (JCP-MH) (www.jcpmh.info) is a new collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists. The JCP-MH brings together leading organisations and individuals with an interest in commissioning for mental health and learning disabilities. These include:

- people with experience of mental health problems and carers
- Department of Health
- Association of Directors of Adult Social Services
- NHS Confederation
- Mind
- Rethink Mental Illness
- National Survivor User Network
- National Involvement Partnership
- Royal College of Nursing
- Afiya Trust
- British Psychological Society
- Representatives of the English Strategic Health Authorities (prior to April 2013)
- Mental Health Providers Forum
- New Savoy Partnership
- Representation from Specialised Commissioning

The JCP-MH is part of the implementation arm of the government mental health strategy No Health without Mental Health. The JCP-MH has two primary aims:

- to bring together people with experience of mental health problems, carers, clinicians, commissioners, managers and others to work towards values-based commissioning
- to integrate scientific evidence, the experience of people with mental health problems and carers, and innovative service evaluations in order to produce the best possible advice on commissioning the design and delivery of high quality mental health, learning disabilities, and public mental health and wellbeing services.

The JCP-MH:

- has published Practical Mental Health Commissioning, a briefing on the key values and principles for effective mental health commissioning
- has so far published thirteen other guides on the commissioning of primary mental health care services, dementia services, liaison mental health services to acute hospitals, transition services, perinatal mental health services, public mental health services, rehabilitation services, drug and alcohol services, forensic mental health services, acute care (inpatient and crisis home treatment), community specialist mental health services, mental health services for people with learning disabilities, and older people's mental health services.
- provides practical guidance and a developing framework for mental health.

WHAT IS THIS GUIDE ABOUT?

This guide is about the commissioning of comprehensive eating disorder (ED) services for people of all ages.

From April 2013, NHS England began to commission ED services. These services range from Tier 4 CAMHS ED units, through to adult specialist ED services. Specialist services include inpatient care and bespoke packages of care for intensive day care services (as an alternative to admission). There is also provision for non-admitted care associated with inpatient treatment including outreach. Tier 4 CAMHS also includes outpatient provision for children and young people with complex ED. In doing this, NHS England will be guided by service specifications developed by appointed Clinical Reference Groups for CAMHS and adult services.

Clinical Commissioning Groups (CCGs) commission CAMHS for children requiring Tier 1, 2 or 3 services and multi-disciplinary adult community ED services. These community-based services will perform a ‘gate-keeping’ function for admission and may also include less intensive day-patient services.
This guide aims to:

- complement these specifications by outlining current provision and detailing the components of a high quality comprehensive ED service
- provide additional information about the nature of ED (with particular reference to factors which affect the utilisation of services and health outcomes)
- highlight the importance of ensuring commissioning for integrated ED services across all ages and the range of severity; from mild to severe ED.

**WHO IS THIS GUIDE FOR?**

This guide should be of value to:

- Health and Wellbeing Boards who will have a key role in integrating local services for people with ED and recognising social care needs of people (particularly those with severe and enduring ED)
- CCGs and local authorities should be informed by the principles highlighted in this guide, and CCGs should collaborate with NHS England to commission integrated care pathways across community and day/inpatient treatment
- NHS England who will be responsible for commissioning specialist ED services for children and adults
- service providers including generic adult and child and adolescent mental health services in addition to specialised ED services
- Public Health England when considering preventive strategies for ED and obesity
- patients and carers to inform expectations about ED services and to engage in discussion about the development of future services.

**HOW WILL THIS GUIDE HELP YOU?**

This guide has been written by a group of ED service experts including experts by experience. By the end of this guide, readers should be more familiar with the concept of ED services and better equipped to understand:

- the nature of ED and the effect that these illnesses have on physical, psychological and social functioning
- the particular aspects of ED which can affect engagement, response to treatment and outcome
- the severity of ED and the necessity for comprehensive specialist treatment close to patients’ homes as early as possible in the course of the illness
- the key components of a comprehensive ED service including the range of treatments and professional groups that should be available for patients with ED
- the need for highly integrated services and comprehensive care pathways to ensure the safe and effective management of patients with the full range of severity of ED
- the risk to patients with ED if commissioning of ED services is not clinically informed and subject to ongoing dialogue between commissioners, service providers, patients and carers.
What are eating disorder services?

**WHAT ARE EATING DISORDERS?**

Eating disorders are mental disorders which are characterised by a preoccupation with food and/or weight and body shape and harmful eating habits.

If untreated an ED will begin to dominate a person’s life. ED impact on psychological functioning, physical health, social wellbeing, education/employment and relationships.

The three most common ED are anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED).

**Anorexia nervosa**

AN is characterised by restrictive eating which results in severe weight loss. This may be accompanied by other weight control measures such as excessive exercise, self-induced vomiting or laxative misuse. Individuals are preoccupied with a drive for thinness, a fear of fatness, and body image distortion. Low weight is associated with multiple physical complications and the mortality associated with AN is the highest of any mental disorder, with some studies indicating that death rates are up to 10 times higher among chronically ill patients compared to the general population1. About 1 in 250 females, and 1 in 2000 males, will experience AN in their lifetime with onset most commonly occurring during adolescence or early twenties23. AN is diagnosed when body mass index (BMI) is 17.5 or less, and severe AN is diagnosed when BMI is < 15 (BMI is weight in kilograms divided by height in metres squared). In children and adolescents, measures such as percentage weight for height or BMI centiles are more appropriate, and growth stunting may be an indication of the disorder. It should be noted that the weight criterion has been removed from the definition of AN in the Diagnostic and Statistical Manual of Mental Disorder (DSM 5).

**Bulimia nervosa**

BN is characterised by the consumption of unusually large amounts of food accompanied by a sense of lack of control over eating (binge) alternating with ‘compensatory behaviours’ such as self-induced vomiting, laxatives, diet pills, diuretics, excessive exercise, and restriction. (For patients with insulin dependent diabetes, insulin restriction is an additional problem which has serious medical consequences). A preoccupation with weight and shape dominates individuals’ lives. Although patients with BN are usually within the healthy weight range, physical complications such as electrolyte imbalance with associated cardiac abnormalities are common and BN is also associated with increased mortality24. In community-based studies the population prevalence of BN has been estimated between 0.5% and 1% in young women25.

**Binge eating disorder**

BED is diagnosed when binge eating occurs in the absence of ‘compensatory behaviours’. As a consequence people with BED are usually overweight/obese. The prevalence of obesity is increasing and the cost to the individual in terms of quality of life, and to NHS resources, is high.

**’Eating disorder not otherwise specified’**

EDNOS is a diagnosis given when the general symptoms of ED exist, but without fitting the exact criteria for one of the above diagnoses. This is the most common form of ED identified in clinical practice. It should be noted that EDNOS is not a milder form of ED, and can be as severe in presentation as any other diagnostic category.

**Other considerations**

Eating disorder presentation often changes over the course of the illness, so it is not uncommon to move between ED diagnoses. Therefore clinical presentation, including risk, is often more important than diagnostic category in determining care pathways.

People with ED often also:

- have other mental health conditions (most commonly mood disorders, anxiety disorders, obsessive compulsive disorders, personality disorders and drug/alcohol misuse), and comprehensive psychiatric assessment is therefore necessary to avoid missed diagnoses
- experience low self-esteem and feelings of guilt and shame
- perceive their ED not as a problem, but as a solution to psychological distress.

These aspects of ED often result in a delay in people accessing treatment, as well as sometimes protracted ambivalence/resistance to engaging with health services. Evidence highlights that delay in receiving treatment is associated with poorer outcome2. Any avoidable obstacles to accessing ED services must therefore be minimised as a priority.

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1. Practical Mental Health Commissioning

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2. Practical Mental Health Commissioning
WHAT ARE EATING DISORDER SERVICES?

ED services are a type of specialist mental health service. They comprise teams of mental health professionals with training in the assessment, risk management and treatment of individuals with AN, BN, BED and the variants thereof. The professions in a team may include doctors, nursing, psychology, psychotherapy, dietetics, occupational therapy, family therapy, social work, physiotherapy and support workers.

Services generally offer a ‘stepped care’ model of treatment, with more intensive support offered to more severely unwell patients. While most patients will receive treatment in community services, some (mainly those with AN) will require an inpatient hospital stay.

Specialist services for ED work closely with general mental health services for both children and adults, primary care, voluntary sector organisations (particularly those organisations working specifically with eating disorders such as BEAT), and physical healthcare specialists.

Many people with ED are living in a family environment, and support for carers is an integral part of service provision.

Outpatient services

Ideally treatment is offered by specialist community-based services close to patients’ homes. This involves the assessment and diagnosis of patients with suspected ED and the identification of physical/psychiatric comorbidity. Outpatient interventions include medical/risk assessment and monitoring, management of concurrent physical and mental health conditions, psychoeducation, psychological (individual, group and family-based; guided self-help and therapist delivered therapies), and nutritional counselling/support in accordance with NICE guidelines.

Day-patient/intensive treatment packages

Enhanced support is offered when a patient is either not able to make changes with lower intensity treatment, or their physical or mental health is deteriorating. Weight loss and/or increased ED behaviours are the most common indication for more intensive treatment. Daycare is also used as a step-down from inpatient treatment. Day-patient care involves multi-disciplinary treatment in a specialist ED service/unit where aspects of inpatient treatment are offered in a non-residential setting, with patients continuing to live at home. This approach allows patients to maintain social links. Flexible and gradual reduction of attendance can also support a patient in returning to independent living.

Inpatient services

Highly specialised 24 hour care by a multi-disciplinary team is necessary in some circumstances for people with ED. This includes where there is a physical health risk, where weight restoration has not been achieved with less intensive treatment, or where the care targets a particular aspect of an ED (e.g. self-induced vomiting, over-exercise). Some patients may require detention under the Mental health Act when it is necessary for their health or safety.

Liaison from the ED service

Patients with ED need episodes of treatment in non-specialist settings (e.g. medical wards, general mental health units). Liaison with other professionals is therefore an important aspect of the specialist service. This includes advice to health professionals on specific aspects of the management of patients with ED and the facilitation of transfer to the ED service when appropriate. Refeeding a starving patient has to be done very carefully to avoid the potentially fatal development of refeeding syndrome when the process is undertaken too rapidly. The MARSIPAN guidelines were produced due to opposing concerns about the problem of under-nutrition in general hospitals among AN patients.
Why are eating disorder services important to commissioners?

1 THE COST OF EATING DISORDERS
Mental health problems represent up to 23% of the total burden of ill health in the UK – the largest single cause of disability. Nearly 11% of England’s secondary care health budget is spent on mental health. Estimates have suggested that the cost of treating mental health problems could double over the next 20 years.27

An estimated 1.5 million EU citizens suffer from AN or BN, with a cost of illness estimate of 0.8 billion Euros per annum.28,29 However, this figure severely underestimates the true costs of ED as key resource items are not included (e.g. outpatient resource use), and the cost of lost productivity of families and indirect costs due to reduced length of life and health are also not incorporated. These broader costs are much higher than the healthcare costs of ED. Furthermore, the most common ED (BED and EDNOS) are not included in this estimate. These disorders are often accompanied by, or lead to, obesity,30,31 and the combination of the two is rapidly increasing and is projected to grow further, with a recent population prevalence rise from 1% to 3.5%.30,32 This is a greater increase than that for obesity or bulimic disorders alone. A 2012 review published by BEAT indicates total annual costs to the UK of £1.26bn-£9.6bn per year. This includes annual healthcare costs of £80-100m, costs of reduced GDP of £0.23bn-£2.9bn, and costs of reduced length of life and health around £0.95bn-£6.6bn.7

2 CHALLENGES RELATING TO THE CLINICAL CONDITIONS
• ED have significant psychiatric co-morbidity and without effective treatment are often chronic and long-term conditions (which can increase the risk for a broad range of physical and mental health problems); AN tends to be protracted, lasting 5-6 years on average straddling a crucial time in a young person’s development.33
• the prognosis for recovery is inversely related to the duration of illness.

Physical morbidity and mortality
• AN has the highest mortality of any psychiatric illness.34
• patients with ED can die from the physical consequences of severe malnutrition, or from suicide
• inpatient units caring for patients with severe ED must be able to offer high standards of physical health care as well as psychiatric care.

Psychiatric comorbidity
• psychiatric comorbidity is the rule rather than the exception in patients with severe ED – the common comorbid diagnoses are depression, anxiety, obsessive-compulsive disorder, personality disorder, substance misuse
• the greater the number and severity of comorbidities, the greater the challenge – the most appropriate treatment setting may depend on a balance of risks (e.g. of self-harm versus starvation).

Severe and Enduring Eating Disorders (SEED)35
• a small proportion of patients (perhaps 40 per million population) will have chronic ED which produce many different problems in the domains of physical health, social functioning and work as well as eating and mental health. Such patients may not be able to recover from their ED, and some may require repeated admissions to medical or ED beds in order to maintain safety, quality of life and personal recovery. To maximise the quality of life for such patients, careful joint-working between primary care, community health services, social services, and secondary and specialist ED mental health services may be required.
• some patients will be able to make incremental gains, but improvements may be very modest at best, and the overall outcome measurement for specialist services needs to take this into account. Figures relating to patients with SEED should not be categorised as ‘treatment failures’ but recognised as inevitable due to the nature of this condition.

3 CHALLENGES RELATING TO CLINICAL PATHWAYS
Diagnostic categories
• the majority of patients with ED will fall into the ‘Eating Disorder Not Otherwise Specified’ category as their disorders will be ‘atypical’ in some way. A patient with AN who has been re-fed is one example – the Body Mass Index (BMI) criterion for AN may no longer be met, but the person’s thought processes may remain unchanged, putting them at risk for relapse.
• BMI alone is not a reliable indicator of morbidity. It is therefore important that services are offered according to clinical need, rather than diagnostic labels alone.

Transition from CAMH to adult services
• the majority of ED develop in adolescence, and if early intervention (see below) is achieved, there need to be agreed shared pathways for those who still require the input of specialist services once they reach the age of 18
• some geographical areas are served by specialist teams across the age spectrum, but in general much more needs to be done to avoid disruptions to care when a young person reaches the age of 18. Service planning, protocols and policies are often frustrated by what can be a very artificial ‘cut-off’ at age 18.
• commissioning arrangements need to take into account the additional time required for the process of transition – meetings between adult and child services, joint assessments/handover of care, which may take six months or more.

Liaison across services

• the concomitant treatment of the psychological and multiple potential physical aspects of severe ED requires effective liaison across teams, services and organisations. There is a particular need for effective joint-working and liaison between paediatric and CAMHS for younger patients, and gastroenterology services and adult ED teams. However many other services may also need to be involved, including cardiology, rheumatology, intensive care and even surgery.
• there are particular issues of responsibility in respect of detained patients on medical wards. The Responsible Clinician role cannot be delegated temporarily to a physician following amendments made to the Mental Health Act in 2008, and two consultants must therefore always be involved, both with responsibilities, and who may be working for different organisations.

Early intervention

• early intervention requires early identification – increasing the awareness of professionals (including training) working outside of specialist ED services is necessary to reduce morbidity associated with ED
• the prognosis for recovery from an ED is much better if it is treated early\(^6\) (it worsens once the duration of illness is past three to five years), and an early intervention model is therefore appropriate for these disorders
• early intervention needs to go alongside prevention, but preventative work is not always commissioned, and its effectiveness can only be judged at a population, rather than an individual level.

4 CHALLENGES RELATING TO COMMISSIONING AND SERVICE STRUCTURE

Geographical distribution of services

• all areas need local access to specialist community services, and although the provision has improved over the past 10 years there are still significant geographical variations
• inpatient treatment is only required for the most severely unwell, and therefore the number of patients from a single county or area requiring inpatient treatment will be small (many areas in England do not have access to specialist inpatient treatment).

Commissioning for severity

• specialist services have a remit to work with the most severely unwell patients. However, this can result in patients who are showing all the signs of developing an ED not being eligible for specialist help until the disorder is obviously manifest and perhaps entrenched. Commissioning on the basis of severity does not promote early intervention.
• there are many examples throughout ED services of patients who have lost further weight because their BMI was not deemed low enough to warrant inpatient admission.
• commissioning for the treatment of patients with lower severity ED, using a stepped care model, would reduce morbidity and consequently reduce the overall cost of ED to the health service.

Disruption to care pathways

• to date, commissioners have generally commissioned community treatment and specialist inpatient treatment together. This approach supported continuity of care, and that wherever possible community-based approaches are used rather than inpatient care. It also facilitates discharge for those patients who do need to come in to hospital, and to foster good working relationships and communication between specialist community services and inpatient units. With new commissioning arrangements it is paramount that NHS England and local CCGs prioritise working together to ensure appropriate integrated care pathways are commissioned.
• in CAMHS, care pathways are more likely to be disrupted at Tier 3. CAMHS are frequently commissioned and provided separately from Tier 4 inpatient and day-patient services. Specialist ED services providing both outpatient and more intensive inpatient/day-patient care are rare.

Gender distribution

• approximately 90% of patients with AN and BN are female\(^7\). The increasing emphasis by the Care Quality Commission and Department of Health on single-sex accommodation has meant that some units are now unable to take male patients in order to comply with the standards. Male patients do not therefore have equal access to services, and they may have to travel much further if they require inpatient care.
• the evidence base is correspondingly smaller for male patients, as most participants in research will also be female.
Why are eating disorder services important to commissioners? (continued)

5 CHALLENGES RELATING TO PUBLIC HEALTH AND PUBLIC PERCEPTION

The anti-obesity message
- the enormous emphasis on the need to contain and reduce obesity and its consequences, and the public health messages about healthy eating and increased nutritional information on foods that is part of the overall campaign, can add to the anguish of patients with ED. Such messages also make it difficult for those treating patients who want to try and get them to expand their repertoire of foods, not exclude ‘unhealthy’ ones.

Myths and stigma
- there are a number of stereotypes and myths about ED which can be very damaging to those with the condition, their families, or professionals working with them. ED are often portrayed in the media as a white, middle class, female illness resulting in the many people not in those groups feeling marginalised. It can be assumed that clinical professionals and commissioners are also influenced by widespread misunderstanding and stigma regarding ED. Certain professions prize thinness to an extent which can increase the likelihood of developing an ED in order to gain entry, and everyone is bombarded with media images of physical perfection, which are often manipulated.

WHAT DO WE KNOW ABOUT THE CURRENT PROVISION OF ED SERVICES?

- **identification of cases** – patients with ED will usually present in primary care some considerable time after the onset of symptoms. Factors that influence help-seeking include: (a) ambivalence or denial of the problem; (b) perceived and true stigma; (c) lack of patient understanding of the help available; (d) inadequate understanding of non-specialist professionals regarding ED. On average General Practitioners (GPs) will see two new patients with ED per year of which a quarter will be managed exclusively in primary primary care. However, in the ‘pathways through primary care study’:
  - only 4% of GPs reported using a published guideline or protocol for managing ED
  - between 58 and 65% of GPs did not use recommended BMI criterion to guide referrals
  - and many GPs felt dissatisfied with the care they are able to give to patients with ED and feel inadequately trained in effective treatment strategies.

- **critical window for intervention** – for patients with a relatively recent onset of ED, the first 3-5 years represent a critical window for intervention – after this period, the likelihood of recovery is reduced.

- **lower severity cases** – specialist ED services are usually only commissioned for moderate/severe ED. Availability of treatment in other settings is generally very limited. This causes delays in accessing effective care and most worryingly patients sometimes lose further weight in order for their difficulties to be ‘taken seriously’. Patients usually feel undeserving of services which is clearly compounded in these circumstances.

- **isolation and social exclusion** – these are often core problems for people with AN, with an estimated 25% becoming dependent on government support or their carers.

- **carer burden** – the burden of ED on carers is high, and delays in accessing appropriate treatment and support increase this. If carers are unable to support the person with the illness effectively this may contribute to further deterioration.

- **geographic variability** – the RCPsych have undertaken three separate surveys of ED service provision in the UK, each of which has identified a poor geographic availability of specialist ED services, with patients outside of London (where services are concentrated) often having to travel long distances from home for treatment. While new services have developed since 2000, many of these do not fulfil the criteria for a specialist service, and raise questions about the adequacy of specialist provision in some areas. The number of specialist consultant psychiatrists remains significantly below that recommended which has implications for the quality of care provided.
SPECIALISED TREATMENT FOR EATING DISORDERS IS NECESSARY

- ED are associated with high levels of morbidity (psychological, physical and social) and AN has the highest mortality of any psychiatric disorder.

- people with AN do not improve spontaneously – studies where people have been made to wait for treatment indicate that their condition either remains unchanged or deteriorates.

- critically, one of the predictors of relapse/recovery is treatment in a general setting where recovery rates are lower and relapse risk is higher than treatment in a specialised clinic – delaying access to specialist treatment increases long-term health costs.

- inpatient treatment is necessary when less intensive treatment options are not effective, or if medical or psychiatric risk indicate the need – partly depending on clinical need and availability of specialist beds, patients with ED are currently admitted to a variety of clinical settings including paediatric wards, CAMH units, acute medical wards, adult mental health units, and specialist ED units.

- many areas in England do not have access to specialist inpatient beds, and as a result care pathways become fragmented for the most severe and complex cases.

SPECIALIST CARE PATHWAYS – CAMHS

There is a considerable variability in the treatments provided for children and adolescents with AN. There are essentially two main care pathways available:

1. Primary care to local CAMHS

The first and most common care pathway is from primary care to a local CAMH service. Such CAMHS often have varying levels of expertise in ED and may have a variable mix of treatments available.

Because of the potentially life-threatening nature of AN, a significant proportion of people will be, at some point, offered treatment in hospital. National figures suggest admission rates of over 35% for adolescents and over 50% for younger patients, while one survey of child and adolescent psychiatric bed use found that more beds were occupied by young people with eating disorders, than any other diagnostic group.

Although some admissions (e.g. those to paediatric wards) can be brief, most admissions are long, with durations of stay commonly between six months and one year and in some cases considerably longer. Where residential treatment has been the main intervention there is evidence that the risk of relapse is high; 25-30% after the first admission and 60-75% for second or further admissions. Treatment in hospital is most often in general child or adolescent inpatient units, some of whom have developed expertise in the area, and less frequently specialist inpatient ED services (mostly in the private sector).

2 Specialist outpatient child and adolescent ED service

The second referral route is to a specialist outpatient child and adolescent ED service (CAEDS). These are dedicated multi-disciplinary services covering a larger geographical area than a single CAMH service. Although these have been growing in number in recent years they are still relatively rare in the UK. Some CAMH services have developed expertise and have “mini-specialist ED teams”, who offer a treatment provision for eating disorders in some ways more like that of the specialist ED service than of a generic CAMHS, but within a single borough. The establishment of a specialist CAEDS has been reported to reduce rates of admission to hospital by as much as 60-80%.
What would a good eating disorder service look like?

This section covers six key areas:

1. ED services for children and adolescents
2. ED services for adults
3. Additional considerations for commissioners
4. Other service components
5. Service standards

1. EATING DISORDER SERVICES FOR CHILDREN AND ADOLESCENTS

Evidence for effective treatments

As summarised below, the evidence suggests that:

- specialised outpatient family interventions are highly effective in treating child and adolescent ED
- specialised services (including specialist mini-teams within CAMHS) can significantly reduce the need for inpatient care
- in areas where there is direct access to specialised outpatient services there is significantly better identification of young people who require treatment
- specialised outpatient services manage the majority of cases themselves without the need for further referrals, providing a consistency of care
- more intensive treatment may be required in up to 20% of cases – this includes admission to paediatric wards, day care, admission to general adolescent psychiatric units and/or specialist ED services.

Clinical trials suggest that family-based therapies conducted on an outpatient basis are effective50, and have excellent long-term outcomes51. These therapies are recommended in clinical guidelines23. The relapse rates for those who have responded well to outpatient family therapy are significantly lower (5-10%) than those following inpatient care49, and there is some evidence that long-term admission may have a negative impact on outcome53, as well as being more costly54. While one study (TOUCAN) showed no significant difference in outcome between specialist individual interventions and general CAMHS, in this study specialist family therapy was not offered53.

More recently a study on care pathways in London found that in areas where specialist child and adolescent outpatient ED services were established, 2-3 times the number of adolescents with anorexia nervosa and EDNOS-AN were identified in services beyond primary care, compared to those areas with only non-specialist CAMHS68. Those patients who commenced treatment in a non-specialist CAMHS had 2.5 times the rate of admissions for inpatient treatment during the following 12 months than those initially treated in a specialist service; and 80% of those seen in specialist services received continuous care without any need for further referrals, as compared to 42% of patients in non-specialist care.

Even with the best outpatient care, more intensive treatment (in paediatric wards, general and specialist psychiatric inpatient and/or day-patient facilities) is required in up to 20% of patients48. Paediatric admissions for ED tend to be shorter than those to psychiatric inpatient facilities, and may divert the need for lengthy inpatient psychiatric admissions. Management on paediatric wards varies a great deal. In some centres, particularly those with specialist ED teams, clear pathways and protocols exist, but in many places this is not the case, leading to inadequate and sometimes inappropriate management. The Royal College of Psychiatrists report, Junior MARSIPAN: Management of really sick patients under 18 with Anorexia Nervosa, provides guidance around these issues26. ED day programmes have more recently been established but the evidence for these has yet to be established.
The previous section highlights the advantages of organising specialist ED services for children and adolescents in a way that enables easy access to outpatient services with specific expertise directly from primary care. The components of a specialist service have been defined as:

1. A service receiving a minimum of 25 new ED referrals per year
2. A multi-disciplinary team, including medical and non-medical staff
3. More than one person with experience of treating ED
4. A team with the expertise to deliver recommended treatments (assessment of physical risk and psychological therapies including family therapy) and the resources to offer routine outpatient treatment.

The specialised team should be able to provide:

1. Family therapy for ED
2. Child and adolescent psychiatric assessment
3. Other evidence-based psychological interventions (e.g. CBT)
4. Access to dietetic advice
5. Medical assessment and monitoring
6. Rapid response to referrals, usually within 1-2 weeks, maximising the chance of avoiding inpatient treatment.

Whilst these can be provided within a ‘mini-team’ in a CAMH service there may be an advantage to develop larger teams with a greater breadth of skills and knowledge. These are not as vulnerable to staff turnover and variation in numbers of referrals.

Patients with ED are at high risk of medical complications. If there is an aim to reduce the need for more lengthy psychiatric inpatient admissions, such risk cannot be managed within outpatient services without clearly defined support and back-up being provided by paediatric/medical facilities. The provision of paediatric care has to be included in planning specialist outpatient services. It is recommended that a ‘Junior MARSIPAN group’ is set up to ensure clear pathways and protocols for the management on the paediatric wards. Paediatric admissions will be for those at acute medical risk to stabilise the physical state. Care should be provided jointly by psychiatric eating disorder and medical/paediatric teams.

The specialised team should be able to provide:

1. Family therapy for ED
2. Child and adolescent psychiatric assessment
3. Other evidence-based psychological interventions (e.g. CBT)
4. Access to dietetic advice
5. Medical assessment and monitoring
6. Rapid response to referrals, usually within 1-2 weeks, maximising the chance of avoiding inpatient treatment.

Paediatric liaison

Psychiatric inpatient/day-patient care

More intensive psychiatric treatment will be required for a minority of patients who (a) deteriorate despite paediatric admissions, and/or (b) where they have not responded well to outpatient treatment, and where the risk cannot be safely held in an outpatient setting.

These are often young people with more complex illnesses (e.g. significant comorbidity such as obsessive compulsive disorder, depression, developmental disorders), or from families where there is limited support for the young person (e.g. because of parental mental health, chaotic or abusive relationships).

A proportion of these young people may require treatment under the Mental Health Act. This more intensive treatment should be provided by day or inpatient services that have specific expertise in the management of severely ill adolescents with ED, and can provide evidence-based treatment. This may be within a specialist ED unit or on a general adolescent psychiatric unit, on the condition that staff have experience in managing these patients on a regular basis. Where patients are referred outside of the service, outpatient services need to establish close links with these facilities to ensure continuity of care, and to limit the need for lengthy admissions.
What would a good eating disorder service look like? (continued)

2 EATING DISORDER SERVICES FOR ADULTS

Anyone with an ED in England should have access to a comprehensive multi-disciplinary ED service. This service must have the resources and expertise to offer assessment of the full range of ED (AN, BN, EDNOS and BED). This service may also have the expertise to develop specific interventions for the management of patients with obesity if appropriately funded.

Clear referral protocols and care pathways should be agreed between ED services, referrers and commissioners. Patients with less severe ED should have timely access to ED services. This is particularly important as we know that a proportion of these patients will develop more severe and/or enduring illness, and that this is more likely if they are denied access to specialist treatment. Early intervention will reduce the morbidity and mortality associated with ED. Currently this initial step in the care pathway is unsatisfactory. Lower severity cases may be seen in primary care or secondary mental health services depending on local arrangements. There is a need for specialist input at this stage of the pathway to ensure identification of cases and optimal access to appropriate treatment using a stepped care model.

The voluntary sector also have an important role in offering advice and support to patients and their families/carers. BEAT is a national charity for people with ED that provides help both through telephone/internet-based helplines and local support groups for patients and carers. There are many other charities and patient-led services that offer support to people with ED. These include First Steps, Student Run Self Help (SRSH), Succeed Foundation, Anorexia and Bulimia Care (ABC), and Diabetics with Eating Disorders (DWED). A high quality comprehensive ED service would have integrated care pathways from identification through to inpatient treatment with commissioning to support patients moving flexibly between different components of care depending on clinical need.

Community eating disorder services (CEDS)

The majority of patients with an ED should be managed in the community close to their home. A community ED service should be able to provide the following:

- comprehensive psychiatric assessment to include ED psychopathology and identify comorbid mental health and physical conditions. Diagnosis should be discussed with patient, carer and referrer.
- risk assessment, both psychiatric and physical. This will include organising relevant investigations (e.g. blood tests, ECG, bone densitometry). Clear arrangements should be made with a patient's GP agreeing responsibility for ongoing physical health monitoring.
- advice to referrer to include: 1) assistance in making a diagnosis; 2) management of physical and mental health; 3) SSRIs in BN and BED, treatment of comorbid depression, anxiety disorder, OCD and psychosis. Vitamins and nutritional supplements should also be considered; 4) when to refer to CEDS.
- a patient-centred, non-judgemental approach utilising motivational interviewing in order to maximise engagement of patients where ambivalence or denial of the difficult aspects of ED are known to influence patients experience of care and outcomes.
- high quality evidence-based psychological therapies for BN and BED (guided self-help-BN/BED; Cognitive Behavioural Therapy CBT-BN, CBT-BED). In the absence of a strong evidence base for specific psychological therapies for AN, services should be able to provide a range of psychological therapies in line with best practice (e.g. SSCM, CBT, Cognitive Analytic Therapy, psychodynamic psychotherapy). Family-focused psychological interventions should also be widely available.
- intensive community treatment for patients whose condition is deteriorating or not progressing.
- collaboration with carers/family with careful consideration of patient confidentiality. Carers' needs assessment should be offered, and appropriate advice and support available in addition to family-based interventions such as carers' support groups and family therapy delivered both to individual families and multi-family therapy.
- nutritional counselling and psychoeducation with the aim of restoring healthy, balanced eating.

Resources should also be available for the development of innovative interventions and care pathways particularly for SEED and ED complicated by features of borderline personality disorder. There is a paucity of evidence in the treatment of these conditions and they carry a high level of health burden, physical and psychological sequelae, carer burden and cost.
Specialist day hospital/inpatient treatment

Referral to a specialist inpatient or day-patient service should be considered in the following circumstances:

- **crisis admission** – where there is high medical or psychiatric risk associated with an ED (e.g. severely low BMI, rapid weight loss of >0.5kg/week regardless of BMI, physical complications of low weight or other ED behaviours, suicide risk)
- **symptom recovery** – for patients who have been admitted in crisis, or for those with low BMI who have been unable to make progress despite appropriate community treatment
- **social inclusion recovery model** – to address a particular aspect of a patient’s ED such as persistent self-induced vomiting, excessive exercising, food avoidance and obsessional or phobic behaviours related to food, weight or eating
- **respite** – time-limited admissions may be necessary for weight stabilisation, and to address social and occupational issues in patients with SEED.

Inpatient/day-patient treatment should comprise all components of care offered in CEDS in addition to:

- a high quality intervention aimed at weight restoration or medical stabilisation or the reduction of severe or resistant behaviours associated with the ED
- skilled refeeding with access to parenteral feeding when needed
- a high quality daily group programme
- appropriate utilisation of the Mental Health Act where risk from low weight, compensatory behaviours or other forms of self-harm deem it necessary
- facilitated joint-working with the CEDS with the aim of robust relapse prevention planning and discharge arrangements.

Most patients with an ED requiring inpatient treatment should be admitted to a specialist ED service. However, in certain circumstances, alternative inpatient facilities may be deemed more appropriate:

- **acute medical unit** – if physical health risk is unstable and cannot be safely managed in the ED service. This is most common in severe low weight, where there is rapid weight loss, complications of refeeding syndrome or when electrolyte abnormalities occur in the context of self-induced vomiting. Other medical complications can also occur. Management on the medical unit may include cardiac monitoring, intravenous infusion and other aspects of high dependency care. Management of the behavioural and psychological aspects of ED should also be addressed by providing one-to-one ED specialist nursing for the duration of the admission. Funding arrangements should be in place to avoid potentially harmful delays. MARSIPAN guidelines should be adhered to throughout this process with regional MARSIPAN policies in place.
- **general psychiatric unit** – in rare situations, patients with co-morbid psychiatric problems may be admitted to generic mental health wards if the needs of these patients would be either more appropriately or safely met in this setting. For example, if a patient’s aggressive or suicidal behaviour merits more intensive psychiatric care and prevents engagement with the therapeutic groups on ED services. Liaison support should be provided from the ED service regarding management of the ED, and rapid transfer of the patient when appropriate.

Patients who do not fall into these categories should be offered treatment at a specialist ED service. Some areas of England have no access to a specialist ED service, and others are not able to offer admission when it is needed due to shortage of beds at a specialist ED service. Improved access to specialist treatment across England through the development of new specialist ED services, and increased capacity in existing specialist ED services, should be a priority for commissioners of comprehensive ED services.

Outcome measures

All ED services should conduct outcome monitoring. As a minimum the following should be recorded:

- HONOS\(^\text{56}\) (ED specific glossary developed by multi-disciplinary group RCPsych) or HONOSCA\(^\text{57}\)
- ED symptoms (EDEQ\(^\text{58}\))
- weight and Body Mass Index
- a measure of patient satisfaction/carer satisfaction.

Potential risks associated with new commissioning arrangements

Commissioners and providers must be aware of the challenges posed by new commissioning arrangements for ED services. Separate funding streams for community ED services and specialist ED services could have a negative effect on patient experience, clinical outcomes and cost-effectiveness. Commissioners of ED services should have a commitment to:

- preventing delays/disruption to patient care due to funding arrangements
- avoiding delays to accessing inpatient treatment as admission at lower weight is associated with longer admission – a move towards earlier admission for shorter periods may improve long-term outcome and cost-effectiveness
• ongoing development and maintenance of integrated care pathways between service components and providers

• maintaining flexibility and flow between different service components (community, daycare, inpatient)

• funding intensive community treatment as an alternative to admission or as a step-down from inpatient treatment – there is a risk that this vital step in the pathway may be compromised

• consider ‘high cost, low volume’ patients rather than service components. In the absence of an evidence base for patients with SEED, services should be commissioned to develop innovative care packages for these patients which may span community, day and inpatient components. Continuity of therapeutic relationships may be an important component of care for this patient group, helping to maintain stability and progress and minimise the need for inpatient treatment.

• reviewing obstacles to clinical care as a result of commissioning arrangements on a yearly basis.

3 ADDITIONAL CONSIDERATIONS

Liaison with other agencies for children and adolescents

Systems for liaison with other agencies, such as education and local authorities, need to be in place. Education, for example, can be severely compromised by long-term illness such as AN, and it may be necessary to involve the local authority in cases where there are concerns that parents are unable to meet the child’s long-term health needs. This may be particularly relevant in those who need protracted or multiple admissions.

Age and transitions

Consideration must be given to supporting the development of age-appropriate services, particularly as we are seeing a rise in early-onset ED (<13 years)\textsuperscript{18}. Improvements in early detection and delivery of developmentally appropriate intervention by specialist multi-disciplinary professionals with these skills and competencies is important.

The ideal approach would be to develop ‘ageless’ ED services with seamless treatment from childhood through to old age. In the absence of this, clear transition protocols need to be in place and excellent relationships fostered between teams with the development of shared competencies to aid engagement with adult services.

Student population

Eating disorders commonly affect adolescents and young adults, many of whom will leave home to study in a different geographical area. Commissioners and providers should be aware of the particular issues that arise in providing a safe and responsive service to this population. Changes of address and GP provider can result in delays in the transfer of care. This is most concerning when inpatient treatment is required. In this situation there should be careful consideration involving all parties as to where treatment would best be provided. This may mean returning to be near to family or other support networks. A House of Commons debate suggested that a patient’s home GP should retain clinical and financial responsibility\textsuperscript{59}. This will need, however, clear communication between the home GP and the GP with whom a patient temporarily registers whilst studying. Students should also be able to register with 2 ED services, one at home and one at their place of study to ensure appropriate care during term-time and holiday\textsuperscript{59}. Commissioning and providers should support creative and flexible arrangements to ensure the provision of optimal specialist care.

Gender

Whilst epidemiological evidence continues to highlight that the majority of individuals with ED are female, it is important to consider the 10% of individuals who are male\textsuperscript{24}. Gender appropriate services should be available to all. ED services should be supported in interpreting policy such as same-sex accommodation sensibly to avoid discrimination against male patients.

Ethnic minority groups

The population of England is approximately 88% white British, six percent Asian, and three percent black\textsuperscript{60}, with predicted future rises in many ethnic minority populations.

People from black and ethnic minority backgrounds in the UK are more likely to experience poorer outcomes from mental health treatments, and are more likely not to engage with mainstream mental health services.

In ethnic minority groups such as the Asian population (which makes up the UK’s largest ethnic group), mental health problems are often unrecognised or not diagnosed. However, we know that suicide
is higher in young Asian females compared to other ethnic groups, and the incidence of ED is increasing at the highest rate in this ethnic group, yet this is not reflected in the cases being referred to, and treated by, specialist services. Therefore, consideration should be given to supporting the development of culturally appropriate ED services in the future.

**Training**

Good collaboration and communication between services and tiers throughout the care pathway for ED is paramount and in this way we can support a truly integrated model of care. Up to 20% of all AN and 40% of all BN is treated exclusively in primary care. However, we know that skilled early intervention has a significant beneficial effect on the course of AN. Therefore, creating resources within specialist ED services to provide wider training to other professionals around screening and appropriate referral on to secondary care, and also awareness initiatives with partner agencies such as education and also ethnic minority groups, should be considered. This will ensure that the expertise from specialist teams can be effectively used to support primary care, non-specialist services, education, social care and other agencies to work in partnership with specialist services towards a truly integrated approach.

**Carer/family involvement**

The role of carers should be supported and utilised within ED services following the principles of the Triangle of Care. The active involvement of carers early in treatment can enhance engagement and improve outcomes for patients and their carers. Eating disorder services should have a carers’ lead who is responsible for co-ordinating information and support for carers. Issues of confidentiality should be addressed throughout treatment. It is paramount that patients, staff and carers are fully informed in issues of confidentiality, and are able to balance the importance of trust with considerations of safety.

**4 ADDITIONAL SERVICES**

Eating disorder services have considerable expertise that could be utilised in the management of other conditions (if appropriately funded).

**Obesity**

Specialist ED services can offer a range of interventions for patients with obesity. These include:

- assessment of (a) eating patterns and existence of BED; (b) psychiatric comorbidity; (c) psychological mechanisms underpinning abnormal eating behaviours; (d) additional impulsive behaviours or borderline personality traits; (e) motivation for weight loss
- pre-bariatric surgery assessment – as above, the presence of BED will inform choice of surgical procedure. Psychiatric comorbidity should be treated prior to surgery as associated with poorer outcome. Impulsive behaviours increase the risk of alternative maladaptive behaviour developing post-surgery.
- psychological therapy – there is increasing interest in the development of innovative psychological interventions as an alternative to, or to complement, bariatric surgery.

**Weight loss in the absence of ED**

Eating disorder specialists are skilled in the assessment of patients where the primary cause of weight loss may not be an ED. Low weight may be identified as a consequence of other mental or physical illness. In these cases there may be an element of ED psychopathology, or body image disturbance may have developed as a result of weight loss and disordered eating. Medically unexplained symptoms relating to weight and eating have the potential to use significant resources in primary and secondary care, and a specialist ED assessment can avoid unnecessary treatment or investigations. Specialist advice on the safe refeeding and management of the psychological sequelae can also improve clinical outcome.

**5 QUALITY STANDARDS**

Commissioners should commission ED services that can demonstrate that they meet the recognised standards for their service.

**NICE**

Key priorities for implementation were identified in guidance published in 2004. The recommendations were as follows:

**Anorexia**

- most patients with AN should be managed on an outpatient basis with psychological treatment provided by a service competent in treatment and assessment of physical risk
- patients requiring inpatient treatment should be admitted to a service skilled in the implementation of refeeding and physical monitoring as well as psychosocial interventions.
What would a good eating disorder service look like? (continued)

**Bulimia Nervosa**
- as a possible first step, patients should be encouraged to follow an evidenced-based self-help programme
- as an additional or alternative first step a trial of antidepressant drugs may be used
- CBT-BN should be offered.

**Atypical eating disorders**
- in the absence of evidence to guide management in this area it is recommended treatment follows that of the ED which the eating problem most closely resembles
- CBT-BED should be offered for binge eating disorder.

**Quality network for eating disorders (QED)**
This is an initiative of the College Centre for Quality Improvement. A quality assurance framework has been developed to provide a set of both core and specific standards.

These standards are structured around care pathways (with specific modules for elements such as inpatient or outpatient care). They are grouped into the following areas:
- environment and facilities
- staffing
- access admission and discharge
- care and treatment
- information consent and confidentiality
- clinical governance
- public health.

The standards can be found at: [www.rcppsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/eatingdisorderservices/qed.aspx](http://www.rcppsych.ac.uk/workinpsychiatry/qualityimprovement/qualityandaccreditation/eatingdisorderservices/qed.aspx)

**BEAT assured standards**
This is a quality standard developed by BEAT using the knowledge and experience of people who have been affected by ED. These can be found at [www.b-eat.co.uk/index.php/download_file/view/102/108/](http://www.b-eat.co.uk/index.php/download_file/view/102/108/)

**Worldwide charter for action on eating disorders**
This is a charter produced in 2006 through collaboration between the Academy for Eating Disorders (AED) and other professional and patient/carer organisations around the world.

The charter identifies six rights of people with an ED and their carers:
- right to communication/partnership with health professionals
- right to comprehensive assessment and treatment planning
- right to accessible, high quality, fully funded, specialised care
- right to respectful, fully-informed, age-appropriate, safe levels of care
- right of carers to be informed, valued and respected as a treatment resource
- right of carers to accessible, appropriate support and education resources.

The charter effectively provides people with ED and their families with a list of basic rights and reasonable expectations regarding treatment and services.

The charter also aims to help patients identify high quality services and practices and to guide them in challenging unhelpful, outdated and anti-therapeutic practices.

Together, these provide the building blocks for quality program and service development.

**MARSIPAN**
As described at the bottom of page 12, the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) report will also be of use to commissioners.
Supporting the delivery of the mental health strategy

The JCP-MH believes that commissioning that leads to good ED services as described in this guide, will support the delivery of the mental health strategy in a number of ways.

Shared objective 1: More people will have good mental health.
Commissioning integrated specialist ED services throughout England will increase access to high quality care for people with ED, improving outcomes throughout the care pathway.

Shared objective 2: More people with mental health problems will recover.
Increased early identification through training non-specialist health professionals, and the commissioning of comprehensive ED services that can offer early intervention, will enable more people with ED to recover.

Shared objective 3: More people with mental health problems will have good physical health.
With increased access to specialist ED services more people will have good physical health monitoring, and better management of the many physical complications associated with ED (due to the expertise within such specialist teams and the development of robust shared protocols between ED specialists and primary care).

Shared objective 4: More people will have a positive experience of care and support.
By commissioning integrated specialist ED services, patients will have access to appropriate levels of care and support from professionals with expertise and experience in managing the many challenges that these disorders present.

Shared objective 5: Fewer people will suffer avoidable harm.
Increased availability of specialist ED services will ensure safe and effective management of the psychological, physical and social aspects of ED. With ED services taking the lead in ensuring that MARSIPAN guidelines are implemented across England, the morbidity and mortality associated with ED will be reduced.

Shared objective 6: Fewer people will experience stigma and discrimination.
By commissioning for training of health professionals, and through collaboration with voluntary sector organisations and engagement in public health initiatives, there will be increased understanding of ED and far-reaching effects on those affected and their families’ lives. By reducing misunderstanding, the stigma and discrimination associated with ED should lessen over time.
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Development process
This guide has been written by a group of ED experts, in consultation with patients and carers. Each member of the Joint Commissioning Panel for Mental Health received drafts of the guide for review and revision, and advice was sought from external partner organisations and individual experts.
Resources and references


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