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Access and Waiting Time Standard for Children and Young People with an Eating Disorder

Commissioning Guide

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Document Status

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Key Messages for Commissioners

Eating disorders are serious mental health problems. They can have severe psychological, physical and social consequences. Children and young people with eating disorders often have other mental health problems (for example, anxiety or depression), which also need to be treated in order to get the best outcomes.

Children and young people with eating disorders, and their families and carers, should be involved at every stage of the commissioning process as well as service delivery and design to ensure services are developed that meet their immediate and future needs.

It is vital that children and young people with eating disorders, and their families and carers, can access effective help quickly. Offering evidence-based, high-quality care and support as soon as possible can improve recovery rates, lead to fewer relapses and reduce the need for inpatient admissions.

The availability of dedicated, community eating-disorder services has been shown to improve outcomes and cost effectiveness. If a child or young person starts their treatment in a general child and adolescent mental health service (CAMHS), they are more likely to be admitted to an inpatient service than those treated in community eating-disorder settings within the following year.

The sooner someone with an eating disorder starts an evidence-based NICE-concordant treatment the better the outcome. The standard is for treatment to be received within a maximum of 4 weeks from first contact with a designated healthcare professional for routine cases and within 1 week for urgent cases. In cases of emergency, the eating disorder service should be contacted to provide support within 24 hours.

Services need to be able to respond to the broader needs of families and carers as well as the child or young person with an eating disorder. This might include supporting the family with techniques to help manage eating disorders in young people, and information about additional support services or expert advice.

Providers of eating disorder services will be required to demonstrate that they deliver evidence-based, high-quality care. This can be supported through the membership of a national quality improvement and accreditation network to produce transparent and accessible data for all stakeholders, including the general public. This will enable providers to assess and continue to improve the quality of care they provide, and ultimately become accredited services.

Training commissioned at a national level will be offered to improve clinical and management skills specifically to meet the needs of children and young people with an eating disorder, and the needs of their family where appropriate. This is vital to providing a viable service that focuses on continuous improvement.

It is the responsibility of commissioners to specify and contract for services that have the right numbers of staff with the appropriate level of skills and competencies. It is then the responsibility of the provider to ensure that the service meets the specification with appropriately qualified and supervised staff to deliver high-quality, evidence-based care. A workforce calculator has been provided to guide these decisions for dedicated, community eating-disorder services for children and young people (CEDS-CYP).

NHS England, clinical commissioning groups (CCGs), local authorities, education providers and other eating disorder services (including adult mental health) should work in partnership to improve outcomes for children and young people with eating disorders and support their transition between services. This is an effective way to increase capacity and share resources to deliver better care.

£30 million of recurrent funding (announced in the Autumn Budget 2014) is available to transform services in England for the treatment of children and young people with eating disorders up to the age of 18 years. This funding is to support the commissioning of CEDS-CYP; any capacity created is to be redeployed to support general CAMHS response for those who self-harm or present in crisis.

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Contents

1 The Access and Waiting Time Standard for Children and Young People with an Eating Disorder

1.1 Who is this guide for and what does it do?

The primary aim of this document is to deliver guidance on establishing and maintaining a community eating disorder service. The eating disorders covered in this guide are outlined in Appendix A along with stories from young people and comments from the perspective of parents and carers. Guidance on treatment methods and highly specialised inpatient and outpatient hospital services commissioned directly by NHS England is outside the scope of this document.

This guide is aimed primarily at commissioners, referrers and providers of eating disorder care who are required to agree service development and improvement plans as part of the contracting process. It sets out how to prepare for the Access and Waiting Time Standard for Children and Young People with an Eating Disorder. This standard will be refined and implemented after baseline data is collected during 2016. The guide is for the full range of commissioners of eating disorder services, which may include the local authority (including public health), education (schools, colleges, and universities), clinical commissioning groups (CCGs), NHS England and commissioning support units.

This guide sets out standards and requirements for providing community-based eating disorder services for children and young people (CEDS-CYP), with related referral to treatment pathways. It describes the referral process that is required to ensure swift access to an appropriate service, the staffing and skill-mix and the commissioning arrangements needed, and how a range of services need to work together as part of a wider child and adolescent mental health (CAMH) strategy. This guide is being published at the same time as the guidance on developing local *Transformation Plans for Children and Young People's Mental Health and Wellbeing* (referred to hereafter as '*Transformation Plans*').

This guide will enable commissioners to ensure that the services they commission work towards achieving the Access and Waiting Time Standard for Children and Young people with an Eating Disorder and improve access for children and young people from *age 8 to 18 years*, which is concordant with NICE guidelines.

1.2 How was this guide developed?

NHS England commissioned the National Collaborating Centre for Mental Health (NCCMH) to develop this guide. The NCCMH created an Expert Reference Group (ERG) to inform the work of the Technical Team responsible for writing this guide and related materials (see Appendix J for members of the ERG and Technical Team). The guide was developed in line with the overarching ambition and principles outlined in Future in Mind, and builds on views from over 700 professionals and 1700 children and young people in its consultation. The transformation plans for CAMHS and this commissioning guide have been shared with the children, young people and parent representatives from the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) programme.

1.3 What is the background to the Access and Waiting Time Standards?

The Access and Waiting Time Standard was created in response to increasing levels of concern about the provision of services for children and young people with mental health problems.

In July 2014, a review led by NHS England of Tier 4 child and adolescent mental health services (CAMHS) identified 3 key areas requiring urgent attention. These related to:

- insufficient inpatient bed capacity
- admissions to age-inappropriate settings
- difficulties in discharge planning and support.

At the same time, the Health Select Committee was conducting an inquiry into children and young people's mental health and CAMHS. Evidence was collected through written submissions and oral evidence from experts and service users through 2013–2014. The final report states:

> 'There are serious and deeply ingrained problems with the commissioning and provision of Children's and adolescents' mental health services. These run through the whole system from prevention and early intervention through to inpatient services for the most vulnerable young people.' (House of Commons Health Committee, 2014)

During the final evidence hearing to the inquiry in July 2014, Norman Lamb, the Minister of State for Care and Support, announced a Children and Young People's Mental Health and Wellbeing Taskforce that would bring together key stakeholders to consider how access and services should be improved. The Taskforce's report, Future in Mind, built on the vision set out in Achieving Better Access to Mental Health Services by 2020 and the Five Year Forward View and proposed a wide range of measures to transform the design and delivery of services for children and young people with mental health needs. These include improving transparency and accountability across the whole system, as well as making further improvements to outcomes.

The Autumn Statement 2014 included additional funds of £30 million per year to implement the proposed transformation of services in England for the treatment of children and young people with eating disorders up to the age of 18. The funding is intended to improve the consistency and quality of eating disorders services, provide new and enhanced community and day treatment care, ensure staff are adequately trained and supervised in evidence-based treatment and effective service delivery, and ensure the best use of inpatient services.

NHS England intends this funding to enable commissioners to align their services with the recommendations set out in the Future in Mind report by reforming available treatment, improving access to appropriate community evidence-based eating disorder care and introducing this waiting time standard.

1.4 What is the Access and Waiting Time Standard for Children and Young People with an Eating Disorder?

The Access and Waiting Time Standard for Children and Young People with Eating Disorders states that National Institute for Health and Care Excellence (NICE)-concordant treatment should start within a maximum of 4 weeks from first contact with a designated healthcare professional for routine cases and within 1 week for urgent cases.

When establishing this standard, the ERG were informed by the latest research findings and best practice consensus relevant to children and young people with an eating disorder, including perspectives from children and young people and their families.

The standard will be refined in 2017 based on evidence that is currently being collated, data gathered on access and waiting times and the forthcoming NICE eating disorder guideline.

1.5 Meeting the Standard

The ability of services to meet this standard will be monitored in 2016. The standard will be refined for implementation from 2017–18. A tolerance level will be set for the percentage of young people referred for assessment or treatment that are to receive treatment within the standard's timeframe. Data collected in 2016 will inform trajectories for incremental percentage increases, with the aim of setting a 95% tolerance level by 2020.

From 2016, services should aim to provide NICE concordant treatment within the above timeframes. Compliance with the standard will be monitored and reports will be made public via the Health and Social Care Information Centre (HSCIC) website from the Mental Health Services Data Set. This will provide a baseline for planning in 2017–18.

1.6 What commissioners need to consider – allocation of funding and timeline

Commissioners are responsible for participating in the development of a Transformation Plan for their local area. They must develop this plan in collaboration with children and young people and their families or carers, as well as commissioning partners and providers. The Transformation Plan must be aligned with the overarching principles and ambitions set out in Future in Mind.

The reduction of inequalities in access and outcomes is central to the transformation of services. Local commissioners are reminded that they should make explicit in their plans how they have taken into account the duties placed on them under the Equality Act 2010 and with regard to reducing health inequalities duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities.

The funds have been confirmed as recurrent, allowing CCGs and providers to plan services with confidence. NHS England will be prioritising investment in areas that can demonstrate strong leadership and robust action-planning through the development of local *Transformation Plans*. CCGs will be asked to provide specific information, including financial plans and locally agreed key performance indicators (KPIs).

The Access and Waiting Time Standard assumes that costs over and above the allocated funding will be found from the continued investment made by the NHS locally.

Through their *Transformation Plans,* commissioners are required to demonstrate:

- How they will spend their share of the resources from the £30 million set out in the Autumn Statement 2014 to deliver evidence-based community eating disorder services and care pathways in line with CEDS-CYP requirements. This might include extending services that are already compliant with this model
- How any capacity released, created, or any resources from the £30 million that is underspent, will be redeployed to support general CAMHS response to those who self-harm or present in crisis
- Allocation of funds and timelines.

CCGs will be notified of the full details regarding the allocation of funds for eating disorders with the publication of the guidance on local *Transformation Plans*. Allocations will be made through the normal revenue transfer process using the CCG allocation formulae. This will help those CCGs who wish to increase short term commissioning capacity to support the planning process and development of Local Transformation Plans.

As set out in section 5.1 of the Transformation Planning Guidance, funding recurrence is conditional on the assurance of the *Transformation Plans*. CCGs and partners must publish their plans that are clear and accessible on local websites.

2 What are eating disorder services for children and young people, and what are the challenges for commissioners and providers?

2.1 Introduction

Service provision for children and young people with eating disorders is variable across England. Services that are deemed to have good practices offer a ‘stepped care’ model of treatment, based on need, with more intensive support offered to those who are more severely unwell. While most people receive treatment in community services, some (mainly those with anorexia nervosa) receive treatment as day patients or inpatients.

The range of service provision means that access to appropriate treatment is inconsistent. Considerable variability exists in referral to treatment pathways for children and young people with an eating disorder. To improve access, commissioners first need to understand the experiences of children and young people and their families or carers.

There are currently 4 main settings that provide access to eating disorder treatment for children and young people. These are generic community CAMHS, eating disorder mini-teams, child and adolescent eating disorder services, and inpatient settings.

This section outlines treatment settings, referral to treatment pathways and the current challenges that commissioners need to address so that they can deliver optimal care.

2.2 Current referral pathways and treatment settings

2.2.1 From primary care to generic community CAMHS

Once an eating disorder has been identified, the first and most common referral pathway is from primary care to local community CAMHS, which often have varying levels of expertise in eating disorders and may have a variable mix of treatments available.

2.2.2 From primary care or generic community CAMHS to eating disorder mini-teams

Some community CAMHS have invested in developing eating disorder expertise and have eating disorder mini-teams, which are able to offer a level of specialist assessment and treatment provision. In general, such teams have the necessary skills ‘in-house’ to provide a full community eating disorder service, but they may be limited in the number of cases they can handle. Some mini-teams have access to home treatment teams or intensive outreach services, which may be able to support children and young people in their own homes for a limited period. Mini-teams tend to serve a smaller geographical area than larger community child and adolescent eating disorder services. Depending on available resources, they may need input from other CAMHS colleagues more widely or form part of a larger eating disorder service.

2.2.3 From primary care, generic community CAMHS or an eating disorder mini-team to a child and adolescent eating disorder service

The third referral route is from primary care, generic CAMHS or an eating disorder mini-team to a community child and adolescent eating disorder service. These are multidisciplinary services covering a larger geographical area than a single CAMH service. Such services offer community-based treatment, usually with the possibility of more intensive community-based or, in a few places, day patient treatment. Although these have been growing in number in recent years they are still relatively rare in the UK (Royal College of Psychiatrists, 2012). Eating disorder services work with generic CAMHS, primary care, paediatric healthcare specialists, schools and voluntary sector organisations (particularly organisations such as Beat [Beating Eating Disorders], who work specifically with individuals with an eating disorder).

2.2.4 Inpatient treatment

Treatment in hospital takes place most often in general psychiatric child or adolescent inpatient units, some of whom have developed expertise in eating disorders, or with an inpatient eating disorder service (mostly in the independent sector). Day treatment is sometimes offered as a step down from inpatient care; alternatively, children and young people are discharged back to the care of their local CAMHS or eating disorder service.

Shorter acute admissions may be arranged for children and young people who are physically compromised in local paediatric wards. In some areas of the UK well-established, effective care protocols exist between local paediatric and mental health services in relation to treatment of eating disorders, but in other areas arrangements are more ad hoc.

2.3 Current challenges to delivering optimal care

There are currently a number of problem areas relating to the care and treatment of children and young people with an eating disorder. There are difficulties inherent to the conditions themselves, as well as to the delivery of treatment. As a result, many families and carers struggle to access appropriate care in a timely manner. This section outlines current challenges that commissioners should address when creating their *Transformation Plans*.

2.3.1 Barriers to identification and engagement

Engagement

In cases of anorexia nervosa, a worried parent, friend or teacher often makes the first contact. The child or young person is typically reluctant to engage with their GP. However, engagement at this stage is key; children and young people are likely to need help and support in accepting that they have a problem and need specialist help. This may not only take time for the child or young person but also require additional time commitment from the primary care practice, which is likely to be already under pressure.

However, some children and young people may not want their family to know about their eating disorder, which practitioners often find challenging because family involvement is usually of great benefit, as recommended by the Eating Disorder NICE guideline (2004). Children and young people should always be encouraged to involve their parents or others with parental responsibility.

Identification

In cases of bulimia nervosa and binge eating disorder, the young person is more likely to be older and to consult alone. The young person may not seek help for the eating disorder directly, but instead present with a range of symptoms secondary to the eating disorder (for example, menstrual disturbances, gastrointestinal symptoms, fatigue, lethargy, anxiety or depression).

(House et al., 2012) suggested that with direct care pathways to specialist eating disorder services, the case identification of anorexia nervosa is approaching the levels identified by epidemiological studies. However, this is not the case for bulimia nervosa and additional and more proactive measures are needed to improve case identification and early intervention for this group.

2.3.2 Barriers to early intervention

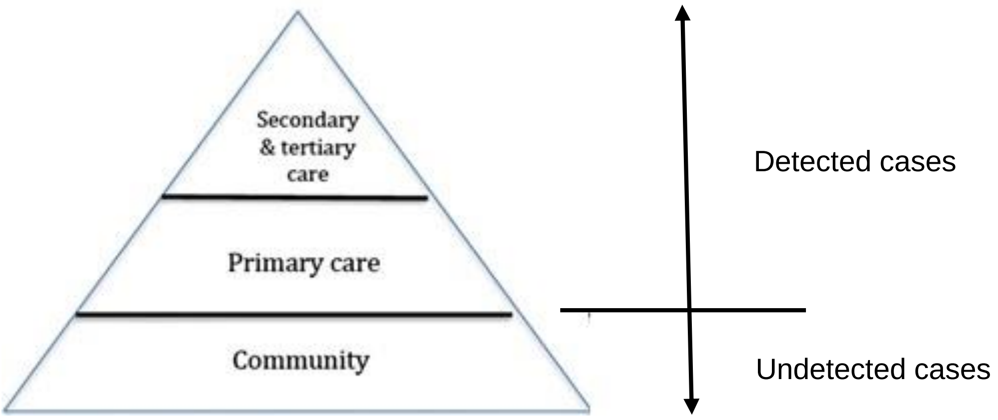
A carer's perspective

Intervention and therapy are just too little too late. So capacity and consistency are issues.

Some research suggests that early intervention results in a better prognosis for recovery and can reduce risk of relapse from an eating disorder. This research suggests that unless intervention is delivered in the first 3 years, the outcome is poor (Treasure & Russell, 2011). Early intervention is hampered by a number of factors, including:

- inadequate understanding of eating disorders
- poor recognition of risks
- poor awareness of local care pathways or eating disorder services
- delay in referral to appropriate services
- delay in treatment, caused by a lack of local eating disorder services, capacity in existing CAMHS or eating disorder services, suitable treatment and appropriately trained professionals.

Figure 1: Incidence of disorders in the community and in the healthcare setting (Micali et al., 2013).



There are reported problems associated with health professionals delaying the provision of appropriate treatment due to their treatment decisions being based primarily on the young person's weight and BMI. These decisions can lead to a delay in access to appropriate treatment. The Eating Disorder NICE guideline (2004) is clear, stating that:

"In anorexia nervosa, although weight and BMI are important indicators they should not be considered the sole indicators of physical risk (as they are unreliable in adults and especially in children)."

Once the possibility of an eating disorder has been considered, sensitive inquiry and following the Eating Disorder NICE guideline (2004) will usually lead to a correct diagnosis and the opportunity to deliver appropriate treatment at an earlier stage thus improving outcomes and reducing the burden on families and carers.

Many children and young people with an eating disorder present to primary care some considerable time after the onset of difficulties. Most will be brought for help by others, although older adolescents may seek help themselves. Early intervention can also be hampered by individual and family factors, specifically delays in help-seeking related to:

- underestimation, unwillingness or inability to recognise the problem
- perception or experience of stigma, contributing to shame or reluctance to seek help
- lack of understanding of the help available.

Young people with severe eating disorders who require inpatient admission are often not being placed in adolescent psychiatric units because of limited or variable bed availability, or are being placed in units far from home. In relation to concerns about access to inpatient mental health services, NHS England commissioned and published the CAMHS Tier 4 Report on current provision and commissioning and, as a result, NHS England is reviewing the commissioning strategy for inpatient services.

Increasing the opportunities for early intervention pivots on

- increasing the awareness of professionals working in primary healthcare, medical, educational and other settings attended by children and young people
- providing appropriate training (including a clear understanding of NICE guidelines) for healthcare professionals
- providing better information about eating disorders
- ability to access eating disorder services directly e.g. via self-referral.

2.3.3 Impact of eating disorders on families and carers

A carer's perspective
The self-blame and guilt are huge. The problems of the eating disorder redefined our family life … and as mum I gave up my job to be able to respond to my daughter's needs.

Eating disorders can have a considerable impact on families and carers, both personally and economically. Eating disorders are costly because, for example, families and carers may be required to make changes to their own employment to care for the child or young person. They can also disrupt family life and activities, and may have a significant effect on siblings. The Future in Mind report states:

> 'All children and young people may experience adverse life events at some time in their lives, but some are more likely to develop mental health disorders e.g. following multiple losses and/or trauma in their lives, as a result of parental vulnerability or due to disability, deprivation or neglect and abuse. These children, young people and their families may find it particularly difficult to access appropriate services, or services may not be configured to meet their psychosocial needs. In addition, they sometimes find it more difficult to access services they may find alienating and may have a lifestyle that is not conducive to meeting regular appointments.'

Further deterioration can occur in the child or young person if families or carers are unable to support them (Treasure et al., 2001). The Annual Report of the Chief Medical Officer stated:

> ‘There is evidence that supporting families and carers, building resilience through to adulthood and supporting self-care reduces the burden of mental and physical ill health over the whole life course, reducing the cost of future interventions, improving economic growth’ (APS Group Scotland, 2012).

Treatment for an eating disorder in a child or young person must include attention to the impact of the disorder on other family members, yet currently this is not always in place. The support needs of families and carers must be considered alongside the child or young person’s treatment needs from the outset.

2.3.4 Inadequate liaison among healthcare providers

Currently, there is significant variability in the effectiveness of collaboration across healthcare services. A lack of collaboration causes confusion, adds to the burden of children and young people and their parents or carers, and has the potential to delay recovery. Effective joint-working to manage the treatment of the eating disorder, any coexisting mental or physical health problems and the physical consequences of severe eating disorders is essential but often not in place.

Eating disorders are now a significant health issue for paediatric medical services, with the incidence matching many more ‘traditional’ paediatric chronic conditions (Hudson, 2012) and outnumbering illnesses such as meningitis for most age groups (Hudson et al., 2012). In particular, the majority of early onset eating disorders (under age 13) requiring an admission to hospital are admitted to paediatric wards (Nicholls et al., 2011). This is set against a background of inadequate training and skills to manage children and young people with an eating disorder and related complications in many paediatric settings in the UK (Hudson et al., 2013), with admissions frequently unplanned, unprepared and sometimes done unwillingly by paediatric teams leading to potential risk and adverse events.

More work is required to establish effective liaison across teams, services and organisations and between community eating disorder services and paediatrics to redress the imbalance currently brought into the system by service variability.

2.3.5 Inadequate liaison with local authorities and schools or higher education

Systems for collaboration between other agencies such as education and local authorities are also often not in place, which can cause particular difficulties for those who need protracted or multiple admissions and in cases where there are concerns that parents are unable to meet the child’s health needs. Poor communication with schools and colleges can result in inconsistent messages and management approaches.

2.3.6 Transition difficulties between services

Disruption due to transitioning between services can happen at different stages of the care pathway. These can be caused by different variables, but 2 important factors are age and geography.

Most young people transition to adult services at the age of 18, which presents problems because that age is associated with a peak period of difficulty for those with an eating disorder. There is a high prevalence of relapse at and beyond 18. For some, recovery from an eating disorder can take several years, and continuity of service is important for successful outcomes. A common problem exists when a young person reaches 17 or 18 and transitions from CAMHS and paediatric to adult services, but still requires the input of specialist mental health services as well as medical care. Transfer of care is likely to involve both a requirement to establish new relationships as well as a shift in treatment approach. Where clear transition protocols are not in place, with adequate preparation for transfer of care, recovery may be hampered.

Older adolescents and young adults may leave home to study in a different geographical area, which can coincide with or exacerbate age-related care-transition difficulties. Change of address and GP provider can result in delays in the transfer of care, and can be particularly concerning when inpatient treatment is required. In addition, the move away from home itself can make the young person more vulnerable due to the potential reduction in familial support, a reduced circle of friends and pressure to make new friends. Risk of onset of an eating disorder or relapse may be particularly high at this time and there is a need for services to work with Colleges and Universities.

A professional's perspective

[Some services are located] far away from home [and some young people] have to travel [up to] 3 hours' round-trip for every appointment.

A few areas are now served by community eating disorder teams for people across the age spectrum (Royal College of Psychiatrists, 2012). Where these are not in place, there remains a significant need to establish shared pathways to prepare for transitions and avoid damaging and costly disruptions in care.

2.3.7 Geographical variability in distribution of services

Provision of community eating disorder services has improved over the past decade, however there are still significant geographical variations. People who live outside of cities with eating disorder services often have to travel long distances from home for treatment (Royal College of Psychiatrists, 2012). This can result in an increased burden on them and their families or carers and increased costs in out-of-area care. In addition, there may be variability in available medical services to support children and young people with acute and chronic healthcare needs.

Only a small percentage of children and young people require inpatient treatment due to the severity of their illness, and therefore the number from a single area requiring this service is small. Consequently, people living in many areas of England do not have easy access to inpatient treatment for an eating disorder and commissioners may not have experience in commissioning inpatient treatment for eating disorder services.

2.3.8 Commissioning for severity

A service user's perspective

You get stuck between 'you are too severe to access community treatment', as you are deemed too incapable of engaging in treatment, and 'you are not severe enough for inpatient treatment'.

Specialist services currently tend to prioritise work with the most severely unwell. Specialist commissioning also focuses primarily on inpatient treatment, which can contribute to the perception that those not requiring inpatient treatment do not need specific eating disorder treatment. Such factors can result in children and young people, who are in the early stages of developing an eating disorder, not being eligible for appropriate help until the disorder becomes more severe and perhaps entrenched. It can also contribute to children and young people feeling that they are not unwell enough to 'deserve' treatment. Commissioning based on severity does not promote early intervention and can detract from achieving good outcomes. Commissioners should base service provision on local need and ensure that they have the resources to support the Access and Waiting Time Standard.

2.3.9 Eating disorder myths and stigma

Individuals with anorexia nervosa are often misperceived as being responsible for their disorder (Crisp, 2005; Roehrig & McLean, 2010). Stereotypes and myths about eating disorders and perceived stigma can contribute to social isolation and reduced quality of life for children, young people and their families or carers. In turn, this can negatively affect the health and wellbeing of those with the condition as well as of their family members (Crisafulli et al., 2008). Stigma-induced shame may act as a barrier to seeking treatment for anorexia and bulimia nervosa, and fear of being stigmatised may cause additional distress (Stewart et al., 2006). The Beat website posted a recent survey on the stigma people with an eating disorder and their family members experienced, and the majority of people confirmed they had been significantly negatively affected. Three areas were consistently identified as needing attention: improving understanding of eating disorders, providing better education and increasing awareness.

2.3.10 External messages about healthy eating

There is a need to contain and reduce obesity and its consequences with public health messages about healthy eating and increased nutritional information about foods. However, these messages can be confusing, especially for children and young people who are vulnerable to developing an eating disorder. They may trigger or accentuate weight or shape concerns, contribute to changes in eating habits and add to the anguish of people with an eating disorder. Media messages about ‘ideal’ weight and shape can also be experienced as distressing and serve to perpetuate eating disorder behaviours.

2.3.11 Difficulties in outcome monitoring

Collecting and analysing clinical and service data is essential to guide improvements in treatment delivery in session as well as at a service and national level. Challenges exist in this area at all levels, these include:

- imposing additional requirements for information on children and young people and their families and carers
- ensuring the appropriate internal infrastructure exists to collect and upload the data
- ensuring that clinicians have the time and opportunity to collect the data and use it in real-time to guide treatment
- limitations of existing outcome measures for eating disorders in children and younger adolescents
- ensuring that the appropriate personnel can access service level data in order to review and improve processes and delivery of care.

2.3.12 The high cost of eating disorders

The number of people directly affected by eating disorders in the UK increased significantly between 2000 and 2009 (Micali et al., 2013). The King's Fund report, Paying the Price: The cost of mental health care in England to 2026, stated that 'service costs for eating disorders in 2007 were estimated to be £15.7 million, with 95 per cent of this related to anorexia nervosa. Costs are projected to increase to £23.8 million by 2026. Including lost employment costs brings the total to £50.6 million in 2007 and £76.4 million in 2026. Lost employment is estimated to account for 69 per cent of total costs' (McCrone et al., 2008a).

Table 1: Number of people with eating disorders and current and projected costs (McCrone et al., 2008b)

	Number of people (million)	**Service costs (£million)**	**Loss of earnings (£million)**	**Total costs (£million)**
2007	0.117	16	35	51
2026	0.122	16[1]	36[1]	52[1]
		24[2]	52[2]	76[2]

[1] Calculated at 2007 prices.
[2] Calculated using real pay and price effect.

Further research into cost economics is needed to build a full picture of the savings that may be achieved by reducing referral to treatment times. Inpatient treatment costs when community services are either not available or break down also need to be investigated further, to identify the potential for cost savings in this area. Eating disorders account for nearly a quarter of all psychiatric child and adolescent inpatient admissions (Tulloch et al., 2008) and have the longest length of stay of any psychiatric disorder, averaging 18 weeks (Royal College of Psychiatrists, 2012). Admissions of 13 to 19 year-olds have almost doubled since 2011, increasing from 959 to 1,815 in 2014. Prolonged outpatient care (sometimes measured in years), non-NICE-concordant treatment and difficulties in transferring care between services also raise the cost of treatment. However, recent research in Germany suggests that day patient treatment may be equally effective at lower cost (Herpertz-Dahlmann et al., 2014).

Commissioners need to commission services that meet the physical and psychological care needs of children and young people with an eating disorder and reduce the effects of increased stress on the physical and mental health of family members. If services in the community are not commissioned effectively this may result in lengthy inpatient stays and repeated admissions. Through early identification and intervention with evidence-based practice, longer-term healthcare costs due to persistent physical and psychological consequences of eating disorders could be avoided.

2.4 Status of the 2004 NICE guideline on eating disorders

The Eating Disorder NICE guideline was published in 2004 and primarily covered anorexia nervosa, bulimia nervosa, binge eating disorder and atypical eating disorders. The need to update the guideline was assessed in 2008 and 2011, and NICE concluded that insufficient evidence had emerged.

In January 2014, it was recommended that the guideline be updated. This decision was based on 3 factors:

- the emergence of new evidence that could impact the guideline recommendations

- the significant changes to the methodology for developing guidelines since January 2004
- the need to include the application of minimal important difference (a statistical model that tries to define the smallest change in a treatment outcome that a service user would identify as important; also known as the ‘minimal clinically important difference’).

There is very little up-to-date guidance on the treatment of children and young people with an eating disorder. When developing this guide, the ERG therefore considered:

- the current (2004) guideline
- possible changes to the 2004 guideline (see Section 2.5)
- how this guide should use current and future NICE-concordant treatments as an integral part of the care pathway.

2.5 Possible changes in the 2017 NICE guideline on eating disorders

Although the detail of the 2017 NICE guideline cannot be anticipated, the surveillance review on which the decision to update the guideline was made outlined the following points for consideration during the update of the guideline:

- The efficacy of day care versus inpatient care. Some evidence has emerged to suggest that day care may be equally as effective for young people with anorexia nervosa as inpatient care but associated with lower cost.
- The role of family interventions in the treatment of eating disorders. Evidence has emerged that may enable more specific recommendations to be made relating to more formalised family therapy. Family interventions are likely to remain a core component of treatment required for eating disorders in children and young people.
- The efficacy of CBT and enhanced CBT (CBT-E) in the treatment of anorexia nervosa, bulimia nervosa and related adolescent presentations.
- The use of guided self-help for some presentations of bulimia nervosa. Most work in this area has been conducted with adults and, to some extent, older adolescents.
- The role of pharmacological treatments. No evidence has emerged to suggest changes to recommendations regarding the use of pharmacological treatments. In children and young people, these are unlikely to be recommended as first-line interventions for managing eating disorders.

2.6 Creating a service to meet current challenges and the Access and Waiting Time Standard

2.6.1 Requirements for a viable and dedicated eating disorder service

It is recommended that CCGs commission a CEDS-CYP that has the appropriate capacity and skill-mix to meet the Access and Waiting Time Standard. This team should deliver NICE-concordant treatment and care via a trained, appropriately supervised and supported team. It is recognised that although small teams can be effective, they are more likely to encounter difficulties in achieving the requirements of a dedicated service and are vulnerable to variations in the level of service user need as well as staff absence or loss of team members.

Recognising that technology is now able to assist disparate teams and individuals in effectively working together, the members of the CEDS-CYP can either be located in the same physical location or can form a virtual team. A ‘hub and spoke’ model or local network model may be appropriate, although such models require a clearly defined structure and clear overall leadership. Regardless of location, it is recommended that the service should meet the following requirements:

- receive a minimum of 50 new eating disorder referrals a year, which are likely to include anorexia nervosa, bulimia nervosa, binge eating disorder and related diagnoses
- cover a minimum general population of 500,000 (all ages)
- use up-to-date evidence-based interventions to treat the most common types of coexisting mental health problems (for example, depression and anxiety disorders) alongside the eating disorder
- enable direct access to community eating disorder treatment through self-referral and from primary care services (for example, GPs, schools, colleges and voluntary sector services)
- include medical and non-medical staff with significant eating disorder experience
- adhere to the standards set out in this guide.

It is recommended that CCG commissioners establish how eating disorder services are currently provided and if they meet the standards in this guide. If they do not meet these requirements, CCGs should work together to either commission a new CEDS-CYP or alter their current service provision in line with requirements and should reference this in their *Transformation Plans*. CCGs that commission services that already meet the CEDS-CYP standards should confirm this in their *Transformation Plans*.

Sections 3, 4 and 5 outline the waiting time standards and service requirements for CEDS-CYP. Supplementary technical guidance will be issued to support data recording and collection.

2.6.2 The evidence base for, and economic benefits, of a CEDS-CYP model

The most cost-effective treatment of anorexia nervosa in children and young people is reported to be delivered by a community-based eating disorder service as opposed to generic CAMHS (Byford et al., 2007), yet these are not uniformly available throughout the country. House et al. (2012) have shown that delaying access to specialist eating disorder treatment may increase long-term health costs:

- children and young people starting treatment in non-eating disorder CAMHS settings have higher rates of inpatient admission in the subsequent 12 months than those treated in specialist eating disorder settings
- unlike those seen in non-specialist eating disorder settings, the majority of children and young people managed in specialist eating disorder settings receive continuous care for their eating disorder without the need for further referrals
- in areas with direct access from self-referral and primary care settings to CEDS-CYP there is significantly better case identification, and therefore early referral for treatment.

Current state of evidence

There is limited service-level research comparing the relative cost and cost-effectiveness of different care pathways for children and young people with an eating disorder, and what evidence exists, focuses on anorexia nervosa. Current projects in the UK include the CostED study (a study of the costs and effects of different types of community-based care for anorexia nervosa). Other recent projects are outlined in the NICE surveillance review, and include:

- a multi-centre randomised controlled trial of the outcome, acceptability and cost-effectiveness of family therapy and multi-family day treatment compared with inpatient care and outpatient family therapy for adolescent anorexia nervosa

- a multi-centre randomised controlled trial of treatments for adolescent anorexia nervosa, including assessment of cost effectiveness and patient acceptability
- a randomised controlled trial of the cost effectiveness of cognitive-behavioural guided self-care versus family therapy for adolescent bulimia nervosa in a catchment area-based population.

Further findings suggest that differences in total health, education and social care cost per child or young person related to treatment setting are not associated with any significant difference in clinical outcomes. In particular, mean total costs for those initially receiving treatment in a specialist eating disorder outpatient setting have been found to be less than mean total costs for those initially treated as inpatients or in general outpatient settings with no differences in overall clinical outcomes identified (Gowers et al., 2007; House et al., 2012). First-step treatment provided by services specialising in eating disorder assessment and treatment have also been found to be associated with lower subsequent need for inpatient care compared with initial inpatient or generic outpatient CAMHS treatment (Byford et al., 2007; House et al., 2012). Dedicated community eating disorder services have been further demonstrated to allow better continuity of care, with the majority of children and young people receiving treatment from the same team (House et al., 2012). This helps to avoid disruptions in care due to transitions and is generally preferred by children and young people and their families or carers (Eisler & Simic, 2014).

The results of these studies are likely to be included in the review of evidence for the updated NICE guideline on eating disorders (2017).

Overall, the findings of lower admission rates and greater consistency of care associated with specialist eating disorder outpatient treatment support a hypothesis of cost effectiveness for accessible CEDS-CYP.

If the existing findings are generalised, investing in the development of CEDS-CYP to support early assessment and treatment of eating disorders could have significant benefits for children and young people, including:

- improving health outcomes through reductions in relapse rates
- improving children and young people's quality of life through greater continuity of care
- reducing hospital admissions
- reducing disruption to school, family and social life.

These improvements could potentially have a dramatic impact upon the NHS as a whole where improvements in healthcare could be seen alongside the ability to re-deploy savings into CAMHS to improve access for children and young people who self-harm or are in crisis, thus creating a cycle of continuous improvement.

A professional's perspective

Beyond the impact on individuals and families of untreated or poorly treated eating disorders, there are long-term financial impacts for the NHS.

Further research is needed to confirm this conclusion. This should include evidence of the savings to be made from additional investment in community eating disorder services (CEDS-CYP), alongside evidence that individual and family outcomes will be enhanced or at least no worse than the current situation. In addition, evidence to support the cost-effectiveness of CEDS-CYP in treating eating disorders other than anorexia nervosa, for example bulimia nervosa, is needed.

Areas that can demonstrate that they are providing successful eating disorder treatments are encouraged to identify and prioritise research gaps and conduct further research, in order to build the body of evidence to help other regions to deliver quality care and treatment.

2.6.3 The benefits to children, young people their families and carers

The benefits expected from implementing the CEDS-CYP model include every child and young person with an eating disorder receiving:

- improved access and reduction in waiting times
- appropriate evidence-based eating disorder treatment, based on their needs
- treatments for eating disorders and coexisting mental health problems from 1 team
- improved outcomes as indicated by sustained recovery and reduction in relapse, and reduced need for inpatient admissions.

> **A professional's perspective**
>
> [Children and young people with eating disorders] have to wait months for an assessment which can lead to further emotional and physical decline [and add] pressure on a family that is already struggling.

Children, young people and their families and carers will benefit from:

- clearer referral routes and a better understanding of how to ask for help in their local areas
- a reduction in the need for
    - transfers to adult services
    - long periods of treatment
    - inpatient admissions with the disruption to school and family life
- more involvement in commissioning services that meet their needs
- improved knowledge and training for all those working with children and young people, including a better knowledge of how to recognise eating disorders and how to access appropriate care when needed.

> **A professional's perspective**
>
> Hospital admissions… can be disruptive to a young person's social, family and educational functioning which in turn can exacerbate their [eating disorder].

3 Referral to treatment pathways

The Access and Waiting Time Standard is that:

Children and Young People referred for an assessment or treatment of an eating disorder will access NICE concordant treatment within 1 week for urgent cases and 4 weeks for routine cases.

Baseline data collected in the first year will inform the tolerance level to be set in 2017–18. The tolerance level will be incrementally increased each year up until 2020. This standard will be refined and implemented from 2017–18.

This section first summarises the key components of NICE-concordant treatment and then depicts the referral pathways in the form of flow charts with the Access and Waiting Time Standard data collection points.

3.1 The key components of NICE-concordant treatment

3.1.1 NICE concordance

The recommendations outlined in this guide are in line with existing NICE recommendations; the ERG has been mindful of potential changes that may be published in 2017.

It is key that throughout the eating disorders pathway the CEDS-CYP provides oversight, support and consultation. The service should maintain this role from the point of referral, through treatment in all settings and during post-treatment monitoring; additionally they should manage risk and relapse. The CEDS-CYP should be the lead service in providing eating disorders care, even if not directly involved in providing all aspects of treatment, for example, during a period of managing physical risk on an inpatient basis.

3.1.2 Key treatment recommendations

The Eating Disorder NICE guideline (2004) was primarily concerned with the treatment of adults. However, key advice for the treatment of children and young people included:

- children and young people should be offered evidence-based family interventions that directly address the eating disorder
- family members including siblings should normally be included in treatment
- interventions may include sharing of information, advice on behavioural management and facilitating communication
- services should offer care that is age-appropriate (there has been an increase in presentations of early-onset eating disorders in those under 13 years), accessible to females and males (there has been a rise in young men and boys presenting) and culturally appropriate.

Clinicians will need to continue to offer NICE-concordant treatment within the framework outlined in this guide.

Treatment should include specialised community family interventions for anorexia nervosa and specifically adapted forms of CBT for bulimia nervosa, in particular CBT-E (Fairburn, 2008). Overall, current evidence for effective treatments for children and young people with an eating disorder remains limited. However, both CBT and family interventions for adolescent bulimia nervosa have some support (Fisher et al., 2010). In addition, there is emerging evidence to suggest that a specifically adapted form of CBT may be effective in anorexia nervosa in young people (Dalle Grave et al., 2013).

It is likely that the update for 2017 will contain new treatment recommendations, but the pathway outlined here has the flexibility to allow for the forthcoming changes.

3.1.3 Key service recommendations

The Eating Disorder guideline (2004) contains specific service recommendations relevant to the treatment of children and young people, as follows:

- most children and young people should be treated in the community
- inpatient admission should be considered where there is high or moderate physical risk
- admission should be to appropriate facilities with access to educational provision and related activities
- when inpatient admission is required, this should be within reasonable travelling distance.

A professional's perspective

A lack of capacity [in eating disorder services] for early intensive work [can result in] a more protracted period of recovery with greater likelihood of transfer to adult services.

In addition, the guideline recommends:

- placing an emphasis on improving early identification
- increasing the responsiveness and flexibility in intensity of community-based care to reduce the need for inpatient care.

3.2 Pathways and timelines

This section contains the Access and Waiting Time Standard ambitions and future requirements for children and young people with eating disorders and describes the referral pathways.

The pathway and service is set up to deliver evidence-based interventions at varying levels of intensity that covers children and young people with a range of needs. At all stages, the principles of patient choice should be embedded and children and young people should receive collaborative evidence based and outcome focused treatment, in order to improve recovery and experience of care.

Timeline

There is a need for mental health services to be available 7 days a week to ensure prompt response to those presenting with acute need and to reduce hospital stays. For example, when a young person is admitted to an inpatient bed over the weekend or at night, the CEDS-CYP will need to be available to provide support to the young person, their family and medical staff on the acute team. While services are being established this may be a challenge as the team will not be fully staffed, but the CEDS-CYP should have a 7 day week service as their goal for when they are fully established, in your Transformation Plans you should demonstrate how you will move towards a 7 day service.

Referral and assessment

The CLOCK STARTS when the request for an eating disorder assessment is received and logged, regardless of the agency making the request.

Note that the clock does not stop until treatment is delivered. In addition to the Access and Waiting Time Standard time points, this guide also provides timelines for assessment to ensure safeguarding. These timelines are recommended practice but are not measured as part of the Standard. Figure 2 depicts the pathway and timelines for referral and assessment.

Referral process

A number of parties may be involved in the initial recognition of an eating disorder. It is essential that clear referral pathways be in place to facilitate swift access to the CEDS-CYP and to avoid unnecessary confusion, distress and delay. The CEDS-CYP must ensure referral pathways are known by all local relevant professional groups likely to come in contact with a child or young person who may have an eating disorder. This will include GPs and primary care workers, paediatric staff, CAMHS teams, schools and colleges, and other relevant professionals working with children and young people. Initial contact may be for consultation and advice about the appropriateness of referral, for information about accessing the service, or to instigate a referral for an assessment.

The CEDS-CYP should have clear online referral forms, and for those unable to access these, clear guidelines for the information required if the referral is received through another process. Specific information will be needed for the CEDS-CYP to be able to designate the referral urgent or routine with guidance provided for this purpose. It is important that each referral is logged and date stamped as soon as it reaches the service. The waiting time *CLOCK STARTS* on the date the referral is received by the CEDS-CYP or generic CAMHs where the reason for referral is for a suspected eating disorder.

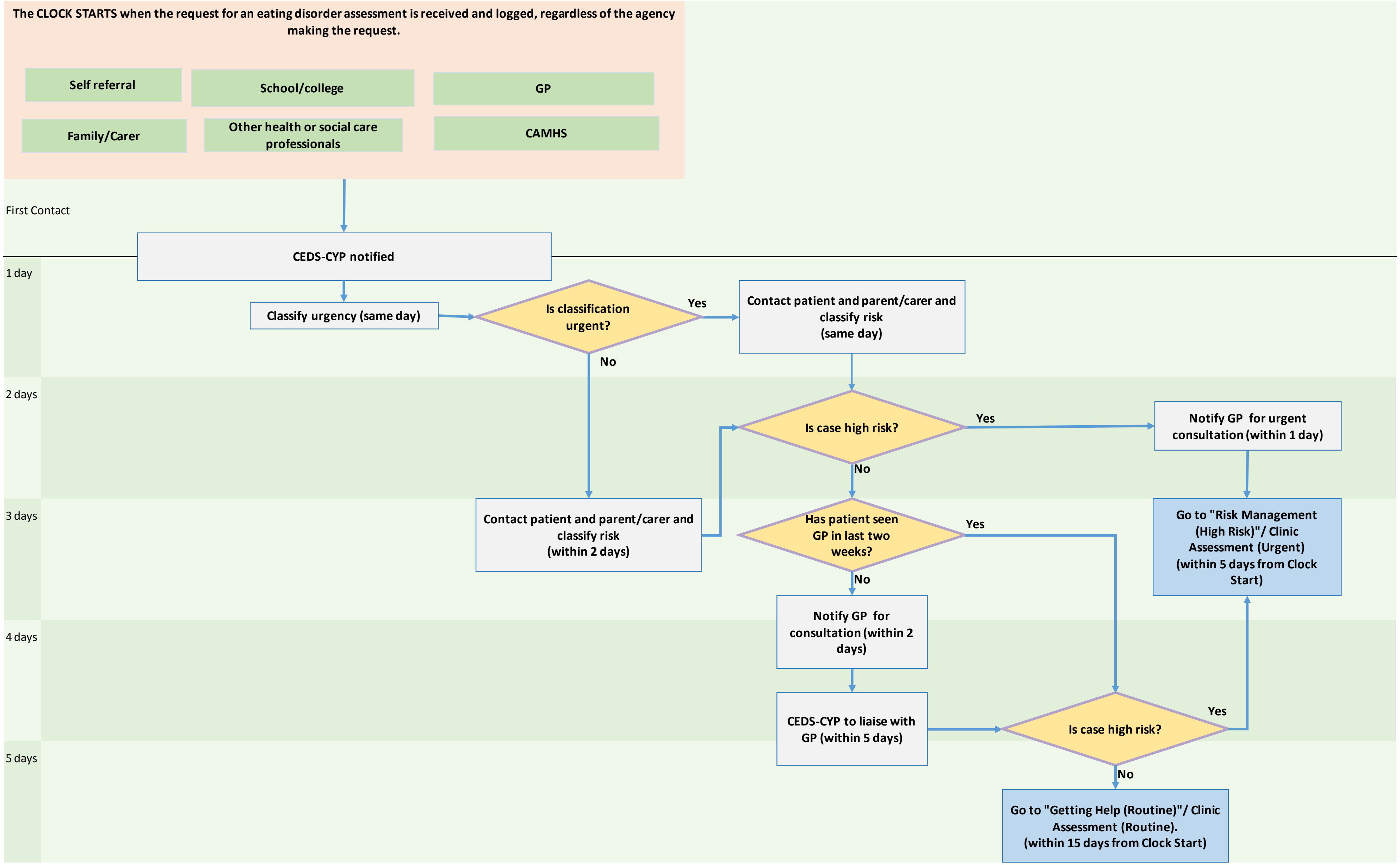


Figure 2: The recommended pathway for referral through to initial assessment

Self-referral by the young person or parents/carers to CEDS-CYP

Young people and their parents or carers may self-refer to the CEDS-CYP or generic CAMHS. Each service should have clear, accessible contact details on a website, which are easy to find via main search engines, with clear instructions in appropriate languages on how to call the service, send an email or complete an online self-referral form. The referral should be logged, and the *CLOCK STARTS* at this time. Young people should be encouraged to self-refer and therefore it is not necessary for them to see their GP in the first instance. At this stage, the name of the GP will need to be ascertained to inform them of the referral. If the young person does not have a GP then the name of a trusted adult will need to be obtained, in case of future non-engagement or if safeguarding issues arise.

GP registration

In order to improve quality of access to GP services, all GP practices in England are free to register new patients who live outside their practice boundary area, depending on the practice capacity at the time.

GP referral to CEDS-CYP

This is an established referral route; however, a *new requirement* will be for the GP to contact the eating disorder service via telephone or electronically following discussion with the child or young person and their parents or carers, as soon as an eating disorder is first identified. The CEDS-CYP should log the date of referral and the *CLOCK STARTS* at this time.

This is important to ensure optimal management is in place from first presentation. Appropriate treatment may include delivery in a primary care setting, under the overall supervision of the CEDS-CYP team. With late presentation, where the child or young person is extremely physically compromised or where there is very high psychiatric risk (for example, suicidality), in a minority of cases, the GP should arrange immediate paediatric and/or psychiatric care to manage risk via local protocols and should inform the CEDS-CYP accordingly. Again, at this point, the date of contact from the GP should be logged and the *CLOCK STARTS*.

GP referral to generic CAMHS

In the absence of a CEDS-CYP the GP may refer directly to a CAMHS. In this case, the *CLOCK STARTS* on the date the referral is received by the CAMH service and it is logged that the child or young person is presenting with an eating disorder or suspected eating disorder.

Generic CAMHS referral to CEDS-CYP

In some instances, the differentiation of an eating disorder from other mental health problems may be difficult in a primary care setting. Alternatively, an eating disorder may develop subsequent to other mental health problems. Some children and young people may therefore be referred to local CAMHS in the first instance, to clarify a diagnosis or for help with other problems such as depression, anxiety, obsessive-compulsive disorder or self-harm. Under such circumstances, if an eating disorder is considered likely, or becomes more evident over time, the CAMHS team is required to make contact with the CEDS-CYP as soon as the possibility of an eating disorder is raised. This should be done by telephone or electronically following discussion with the child or young person and their parents or carers, the date of referral should be logged and the *CLOCK STARTS* at this time.

If an eating disorder is subsequently confirmed as the primary presenting problem and psychiatric risk managed, the CEDS-CYP should in most cases deliver treatment for the eating disorder. This will include managing common coexisting mental health problems such as depression and anxiety disorders. If an eating disorder is confirmed but it coexists with another mental health problem associated with risk, shared care arrangements may be needed between CAMHS and the CEDS-CYP. Under such circumstances, the CEDS-CYP should take responsibility for management of the eating disorder.

Paediatric or other healthcare setting referral to CEDS-CYP

In some instances, the identification of an eating disorder may be difficult in a primary care setting as the presenting complaint may be a physical one. For example, there may be concerns about weight loss without an obvious cause. This can be the case particularly in those aged under 13 where eating disorder behaviours and cognitions may not be readily evident at first presentation to the GP. Some children and young people may therefore be referred to another healthcare professional in the first instance. Alternatively, other healthcare professionals may be the first to identify signs and symptoms of an eating disorder. This may include paediatricians, gastroenterologists, dentists, endocrinologists, gynaecologists, dieticians and other child healthcare workers. Under such circumstances, the healthcare professional is required make contact with the CEDS-CYP as soon as the possibility of an eating disorder is raised. This should be done by telephone or electronically following discussion with the child or young person and their parents or carers. The date of referral should be logged and the *CLOCK STARTS* at this time.

If an eating disorder is confirmed as the primary presenting problem and any medical condition or associated risk managed, the CEDS-CYP should in most cases deliver treatment for the eating disorder. This will include managing common physical aspects of the eating disorder. If an eating disorder is confirmed but it coexists with another medical condition or mental health problem associated with risk, shared care arrangements may be needed between the GP or paediatric service and the CEDS-CYP. Under such circumstances, the CEDS-CYP must take responsibility for management of the eating disorder.

Referral via school or college to CEDS-CYP

Staff in educational settings may be the first to become aware that a child or young person may have an eating disorder. Local guidelines should continue to be followed, to include recommending that the child or young person seeks assessment with their GP. However, if this is declined by the child, young person or family, school nurses or medical, pastoral or other members of staff may make the initial referral to the CEDS-CYP. Under such circumstances, parents or carers and the child or young person should be informed before school or college staff make the contact as they may prefer to do this themselves. In the event of the family not sharing the same level of concern, school staff should still proceed but should make this known to the family and also inform the eating disorder service about the difference of view. The date of referral should be logged and the *CLOCK STARTS* at this time.

Referral via a non-healthcare worker to CEDS-CYP

A range of other workers in contact with children and young people in non-healthcare settings may encounter someone with an eating disorder and can contact the eating disorder service. Examples in non-healthcare settings include social workers, youth workers, sports coaches, dance teachers and other support workers, all of whom may identify a possible eating disorder. Local guidelines should continue to be followed, to include recommending that the child or young person seek assessment with their GP. However, if this is declined by the child or young person or their family or carer, a referral can be made to the CEDS-CYP. Under such circumstances, parents or carers and the child or young person should be informed before contact with the service is made as they may prefer to do this themselves. In the event of the family not sharing the same level of concern, the individual can still proceed but must make this known to the family and also inform the eating disorder service about the difference of view. The date of referral should be logged and the *CLOCK STARTS* at this time.

3.2.1 Referral to initial assessment response times

A referral from any of the above will usually be made by telephone, via email or online. The *CLOCK STARTS* as soon as a request for the CEDS-CYP to assess the child or young person has been received and date of referral logged.

If the child or young person is under 16 then it is essential that a parent or responsible adult is part of the initial contact. If the child or young person is over 16, consideration could be given to initial contact with them alone, especially if they have self-referred; however, family involvement should be strongly encouraged.

Step 1: Classifying risk and urgency

- The CEDS-CYP must *classify the urgency of the case within 24 hours*. The designation of an urgent or routine referral should be based on the information received. Where possible inform the GP that a referral has been received within this time period.
- All require telephone or in-person contact to be made with the child or young person and the parent or carer *on the same day* to clarify risk. The perception of risk from the referrer’s perspective should also be clarified. This rapid response is essential when it is not known if the child or young person is under the care of a healthcare professional and the level of risk remains unclear

At this stage, over the phone, the CEDS-CYP is required to identify the domains of risk to which the child or young person is thought to be exposed at the time of classifying the referral urgent or routine. This may include: physical risk; psychiatric risk (to include risk to self); safeguarding; or other area of risk (e.g. risk to others).

If the child or young person *is deemed to be at high risk*, i.e. in need of urgent medical stabilisation or at high psychiatric *risk the CEDS-CYP must arrange an in person assessment within 24 hours*. This option should be available at any point during the pathway.

Depending on the risk, the case will then follow either the urgent or the routine pathway.

Step 2: Following the appropriate risk pathway

A risk assessment is a detailed clinical assessment that includes the evaluation of a wide range of biological, social and psychological factors that are relevant to the individual and, in the judgement of the healthcare professional conducting the assessment, relevant to future risk, including suicide and self-harm. For further information on physical risk, see Appendix A. The Self Harm NICE guideline (CG16) contains recommendations on the short-term management of self-harm. At the first in-person appointment with the CEDS-CYP they must conduct a full clinical assessment to include a risk assessment.

- If the pathway has been classified as urgent, the GP should be notified and the child or young person should be seen by the CEDS-CYP *within 5 days from the clock starting*
- If the pathway has been classified as routine and the child or young person has not seen their GP within the past 2 weeks, they should be directed to their GP for a consultation *within the next 2 days*. The CEDS-CYP should *liaise with the GP by day 5* following the

clock starting. If there is no GP the CEDS-CYP should see the child in person *within the next 2 days*

Step 3: GP conducts an assessment (in the event of a routine case not seen immediately by the CEDS-CYP)

The GP should assess physical health and look for any other signs or symptoms that suggest high risk.

- If child or young person is found by the GP to *be acutely physically compromised* requiring immediate paediatric care, local acute paediatric protocols should be followed and the CEDS-CYP informed accordingly. CEDS-CYP will take over eating disorder assessment and treatment
- If the child or young person is found to be at *high psychiatric risk* (for example, suicidal), local risk management protocols should be followed and the CEDS-CYP informed accordingly. CEDS-CYP will take over eating disorder assessment and treatment
- If the presentation is reported by the GP to be associated with urgency *(but at a level of risk that has not required immediate action)* an assessment should be offered with the CEDS-CYP as soon as possible and *within 5 days from the clock starting* (i.e. the case now follows the urgent pathway).
- If the presentation is confirmed by the GP as routine, an assessment should be offered with the CEDS-CYP *within 15 days of the clock starting* (that is, the case now follows the routine pathway) plus:
    - information and advice about locally available support services, useful books and information literature should be sent to the family
    - arrangements should be made for the child or young person to be monitored by the GP on a weekly basis until the assessment appointment. If the child or young person's condition deteriorates, a more urgent appointment will need to be offered.

3.2.2 CEDS-CYP clinic assessment

Following the first clinic assessment appointment the following should be known:

- the type and duration of eating disorder
- an understanding of the maintaining factors of the disorder and any protective factors (for example, within the family)
- the physical, psychological and social consequences of the disorder
- the presence and severity of coexisting mental
- and physical health problems
- current medical risk and whether inpatient stabilisation is needed
- current psychiatric risk (to include significant self-harm) and whether inpatient stabilisation is needed
- whether the child or young person has already received any NICE-concordant treatment for eating disorders
- the strengths, resilience and capacity of the family to manage treatment in the community

A service user's perspective

At times, I was very suicidal waiting to access treatment with no interim care. You feel isolated and feel you cannot cope with the illness that is manifesting itself physically.

- the level of motivation of the child or young person and their family or carers to engage in treatment, including those aspects of motivation that may not be immediately apparent or are hidden by feelings of despair and hopelessness
- the degree of confidence on the part of the child or young person that they will be able to make use of treatment.

Based upon this information, the service will establish which setting is the most suitable for delivery:

- community treatment via the CEDS-CYP
- intensive community (to include home treatment) or day treatment care via the CEDS-CYP
- management in the primary care setting, with supervision from the CEDS-CYP.

Where an eating disorder is unlikely

- The child or young person should be discharged back to the care of their GP or to the referring service.

3.2.3 Risk management (high risk)

Figure 3 depicts the pathway for assessing risk in urgent cases and intensive day treatment is delivered where admission is deemed unnecessary to manage such risk. The timeline is depicted down the left-hand side.

A professional's perspective

In situations of high risk, it may be appropriate to do a home visit [if the young person is struggling to engage].

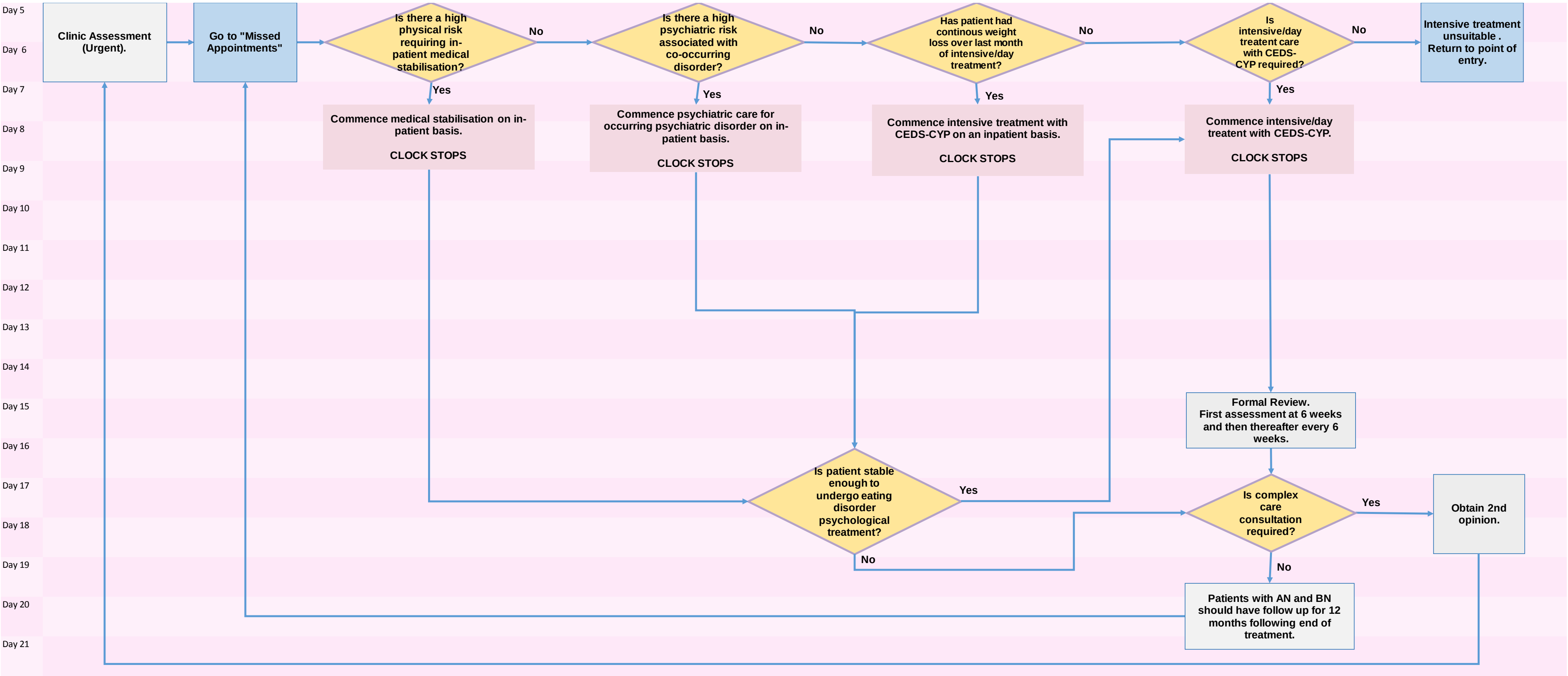


Figure 3: The recommended pathway for managing high-risk cases through to treatment

Eating disorder confirmed

The GP may have completed a risk assessment to establish whether inpatient management of a physical or coexisting psychiatric risk is present before the diagnosis is confirmed by the CEDS-CYP. If a risk assessment has not been conducted, this should occur as part of the CEDS-CYP assessment. It is recommended that unless medical or psychiatric risk is deemed very high, early admission should be avoided and day patient or community care offered in the first instance.

High-risk inpatient management

The CEDS-CYP service is a community-based service. Contracts must be in place with CAMHS and paediatric services to ensure inpatient services are in place for the treatment of physical and mental health needs. The CEDS-CYP should ensure regular review of eating disorder treatment throughout admission.

- Where medical and *psychiatric risk* (risk to self or coexisting mental health problem) *is high*: the most appropriate inpatient service or inpatient setting available should be used.
- If admission is to a general psychiatric or to a paediatric unit the CEDS-CYP should liaise closely with the inpatient team to ensure the eating disorder is appropriately managed alongside the treatment of the coexisting condition or physical needs. A detailed written plan should be established between the CEDS-CYP team and the other treating team. *The CLOCK STOPS at the day the first session of NICE-concordant treatment for the eating disorder is delivered and the date of delivery should be logged.*

Inpatient care may be needed where the child or young person comes from a family where there is limited support (for example, because of parental mental health problems or other forms of psychosocial adversity). Although this is relatively rare, when it does occur it can be difficult to manage. Inpatient care may be the only immediate option but this should always be considered alongside other therapeutic interventions (for example, therapeutic foster care, intensive work with parents to prepare and equip them for future community work). Older adolescents may require regular individual longer-term therapy, involving social care for additional support.

Table 2 describes some admission options for children and young people with an eating disorder who are at high risk.

Table 2: Settings for inpatient admission

	High medical risk **(The child or young person requires inpatient admission for physical stabilisation)**	**High psychiatric risk** **(The child or young person requires inpatient admission for safety reasons or for acute management of a coexisting mental health problem)**
Bed in general psychiatric unit without recognised eating disorder expertise		• Admit child or young person. • CEDS-CYP liaises closely with inpatient team. • Treatment for the eating disorder must be overseen by the eating disorder service alongside the treatment of the coexisting condition. • The *CLOCK STOPS* on the day the first NICE-concordant treatment session is delivered.
Bed in paediatric inpatient setting	• Admit child or young person. • The CEDS-CYP team should commence discharge treatment planning from day of admission and liaise with and support the medical team. • The *CLOCK STOPS* the day the first NICE-concordant treatment session is delivered.	
Specialist eating disorder bed in general psychiatric unit **Or** **Bed in eating disorder unit**	(NB: a few eating disorder units may be staffed and equipped to cope with medical risk)	• Admit child or young person. • Eating disorder managed alongside the treatment of the coexisting condition. • The *CLOCK STOPS* the day the first NICE-concordant treatment session is delivered.

Intensive community treatment

- Where severity is high and risk considered manageable in the community, NICE-concordant intensive community (to include home treatment) or day treatment care should be offered by the CEDS-CYP. Regular assessments need to take place and physical monitoring needs to take place on a weekly basis.
- The *CLOCK STOPS* on the day the first session of NICE-concordant treatment is delivered.
- Intensive treatment should be provided by services that have specific expertise in the management of severely ill children and young people with an eating disorder, and can provide NICE-concordant evidence-based treatment. Appropriately resourced and supervised home treatment can be delivered as an adjunct to the evidence-based programme, but should not be provided instead of evidence-based treatment.

3.2.4 Getting help (low risk)

Figure 4 depicts the pathway for assessing and treating routine cases after the possibility of an eating disorder has been identified. The timeline is depicted down the left-hand side, starting at day 21, which would be the latest date of a clinic assessment in a routine case.

Eating disorder confirmed - Routine community-based treatment

Where severity is deemed moderate and risk considered manageable on a community basis, NICE-concordant community-based treatment should be offered. This should usually be provided by the CEDS-CYP. However, a minority of children and young people, a CAMHS route might be preferable. Where there is a good therapeutic relationship already established in CAMHS and the child or young person and their family or carers want to continue with treatment there, or where coexisting problems or other issues (such as school or safeguarding) might be better addressed by the local CAMHS team or a co-working arrangement. Under such circumstances, the CEDS-CYP should provide consultation and supervision for the treatment of the eating disorder. The *CLOCK STOPS* the day the first session of NICE-concordant treatment is delivered.

Where severity is deemed mild and risk considered manageable on a community basis, NICE-concordant community-based treatment should be offered. This should usually be provided by the CEDS-CYP. However, for some milder presentations supportive eating disorder treatment may be provided in a primary care setting with treatment being delivered by appropriately trained eating disorder staff. If treatment is delivered in a non-eating disorder, supportive setting, the CEDS-CYP must oversee treatment and provide consultation and supervision. The *CLOCK STOPS* the day he first session of NICE-concordant treatment is delivered.

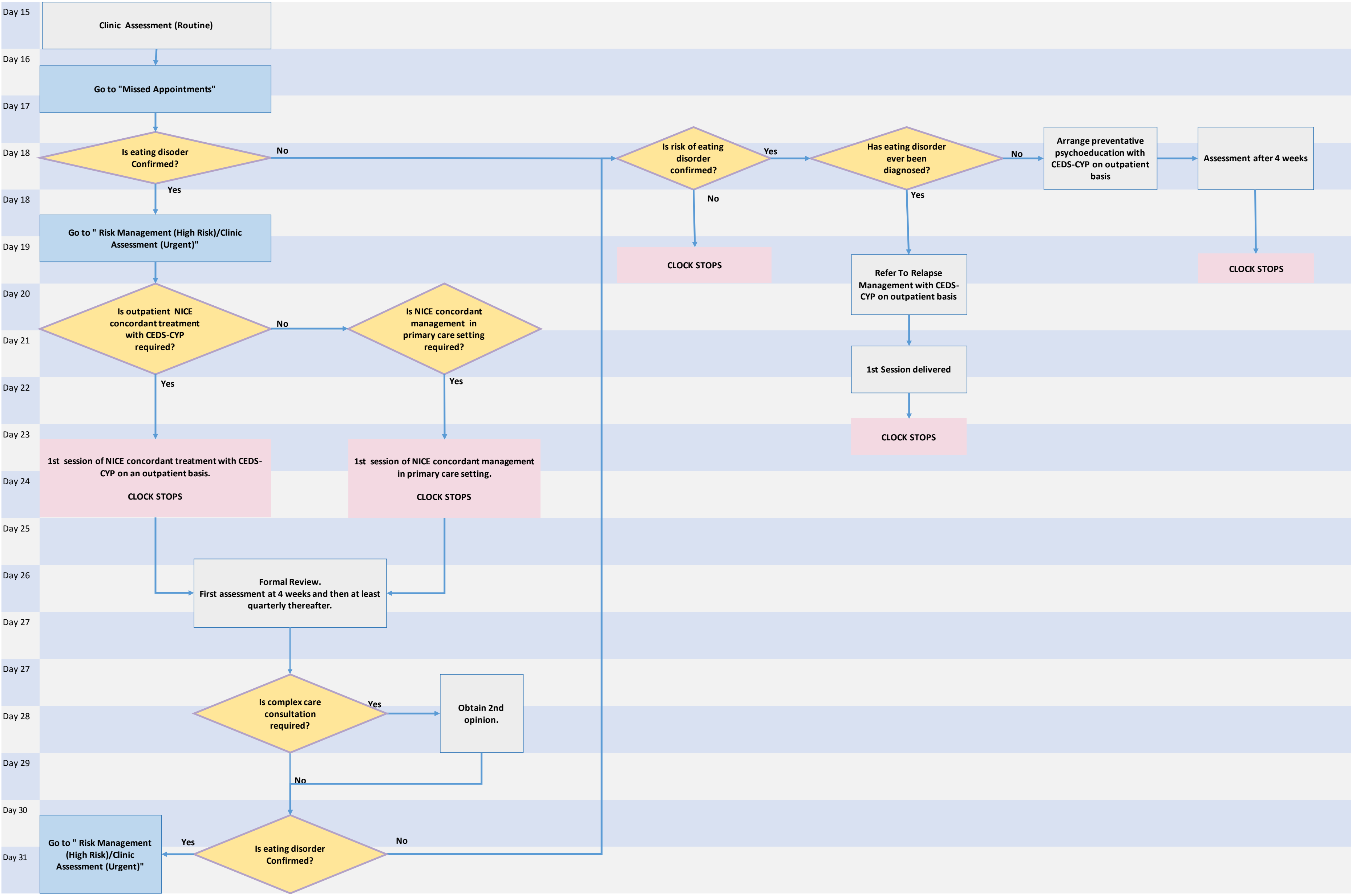


Figure 4: The recommended pathway for managing routine cases through to treatment

Eating disorder not confirmed

The Clock Stops on the day that no eating disorder is confirmed. However, where the *risk of an eating disorder is considered present* and/or the individual has been diagnosed with an eating disorder in the past, the eating disorder service should consider providing some psychoeducation or relapse management sessions.

If no eating disorder has been diagnosed in the past and no eating disorder identified, the individual should be discharged back to the GP with advice. The GP should consider a review appointment in both cases.

Where *the likelihood of another condition is identified*, onward referral should be made to the appropriate service and the child or young person discharged from CEDS-CYP.

Where *no clinically significant problems are identified*, the child or young person should be discharged back to the GP with advice for managing the presenting concerns. In this instance, the GP may need to check if there are continuing unexplained or distressing symptoms.

3.2.5 Management through all stages of the referral to treatment pathway

Capacity and information sharing

The issues of competency and information sharing have been the subject of much research, however it is not within the remit of guide to advise clinicians in this area, but only to draw their attention to the complex nature of decisions related to information sharing and capacity. It is known that there is a high level of ambivalence about accessing care amongst children and young people with eating disorders and compulsory treatment is a contentious issue. Research shows that even when formal compulsory treatment orders are not in place, patients can be exposed to compulsion and coercion (Tan et al., 2010). Research indicates that additional considerations (not captured by traditional legal approaches) might be needed in relation to the treatment of children and young people with anorexia nervosa (Tan et al., 2006).

While every effort should be made to encourage children and young people to involve their parents in their treatment, there will be occasions when children and young people do not want their parents to know about their eating disorder. When children and young people have the capacity to make a decision (are ‘Gillick competent’) their wishes should be respected. At the same time, Lord Fraser said in Gillick that the case is not a licence to exclude parents. When children with capacity insist that their parents should not be involved in, or even have knowledge of, the proposed care, his guidance (the ‘Fraser guidelines’) should be followed.

These principles apply not just to consent to the care itself but to sharing information about it. They are especially significant when that care involves multi-agency working. However, there is still a lot of uncertainty about them. Practitioners need to be fully supported in applying them.

Guidelines on capacity and information sharing should be always be followed, see Appendix C for more information on capacity and information sharing. The Working together to safeguard children website has more detailed guidance. Paragraph 12 and 13 of the Mental Capacity Act 2005 Code of Practice contain information with respect of 16 and 17 year olds.

Children and young people who decline treatment

GPs, and other practitioners as appropriate, can play a vital role in supporting the child or young person and their family or carers when treatment is declined. Every effort should be made to engage with children and young people who refuse treatment. The goal should be to provide support and help them accept the need for treatment over time. See Appendix C for guidance on information sharing and capacity.

When the refusal of treatment places a child or young person at risk of significant harm, lawful and proportionate steps can be taken to control or reduce that risk.

If someone aged 16 or over is assessed as lacking mental capacity, steps may be taken in their best interests in accordance with the Mental Capacity Act 2005 and its Code of Practice.

The above principles apply to the recording and sharing of confidential personal information as they do to the wider provision of care or treatment.

Managing appointments

The young child or young person’s choice should be respected when booking appointments and patient initiated delays should be balanced with risk management, e.g. someone deemed to be suitable for routine care pathway may choose to attend an exam to have the first appointment in a month’s time, this choice should be taken into account when booking appointment. Patient choice will be accounted for when reporting on referral treatment times.

Managing missed appointments

Figure 5 depicts the pathway for managing missed appointments.

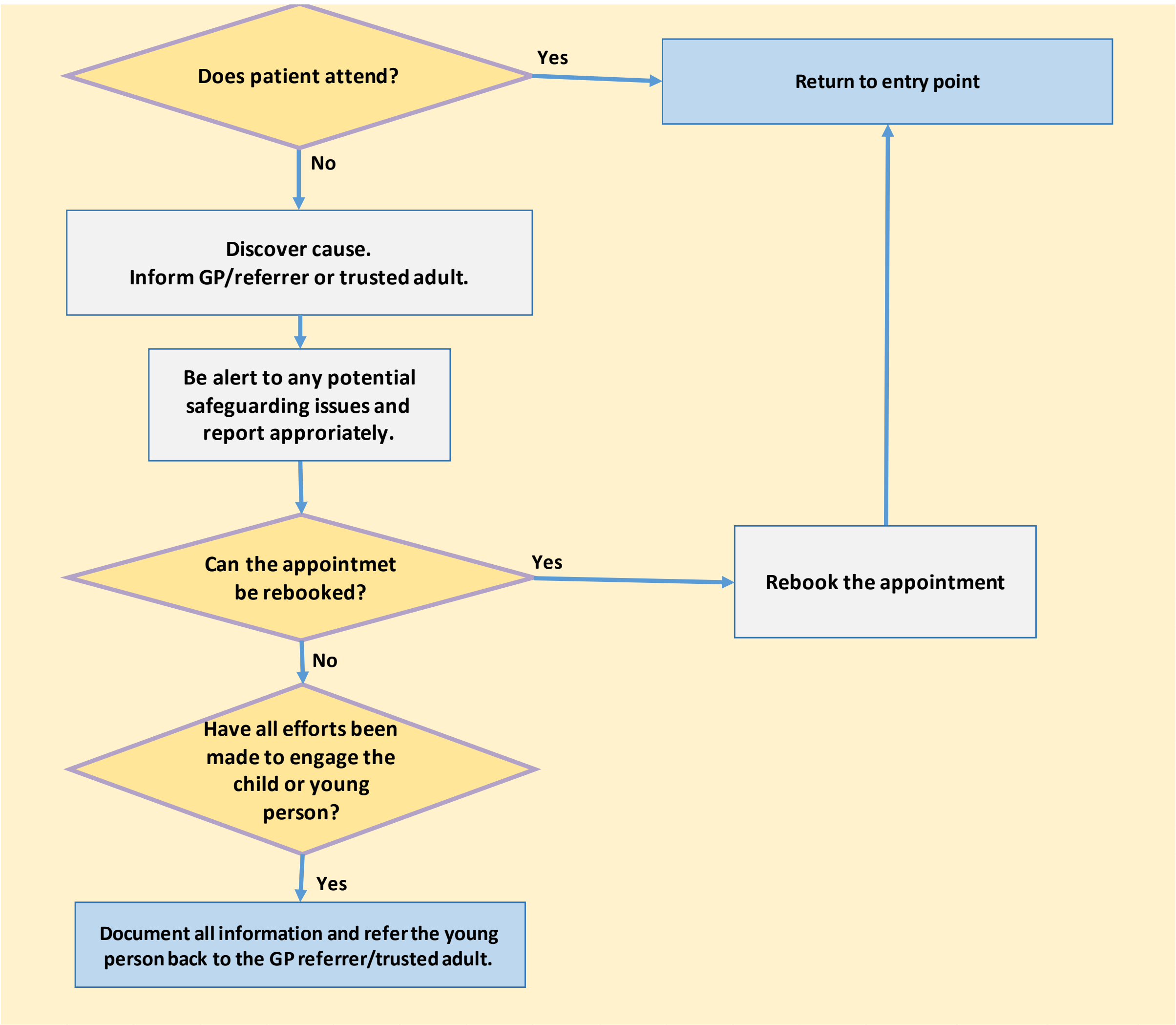


Figure 5: The pathway and Access and Waiting Time Standard time points for missed appointments for assessment

The reasons for missing appointments are varied and it may be difficult to assess these properly over the phone. However, every effort should be made to do make contact and engage with the young person and family. The service should be aware that a missed appointment could be a safeguarding issue.

Where an appointment needs to be rebooked, clinicians should work to do this at the earliest possible time. Every effort should be made to ensure access to care continues and help is provided in a timely fashion. The causes for missing an appointment should be investigated carefully, and the referrer and the GP/trusted adult informed. Any efforts made in this respect should be recorded in the child or young person’s clinical notes. It is recommended that an appointment should be booked to take place within 2 working days of the missed appointment to ensure that risk is managed appropriately.

If a child or young person repeatedly misses appointments and no further appointments can be made despite the best efforts of the clinician to encourage engagement, the child or young person should be discharged back to their health care referrer, if appropriate, and GP/ trusted adult notified. All referrals back to the GP need to be recorded and justified with a clear record of attempts made to re-engage and contact the child or young person and, where appropriate, their parent or carer

The policy is based upon the following considerations:

- In the majority of cases the GP is the locus of continuity of care, which is of primary importance until the child or young person is ready to rebook the appointment. GPs have the responsibility to engage with the child or young person while being mindful of the wishes of the child or young person.
- It is important that there is clarity around who holds clinical responsibility for a child or young person. If the CEDS-CYP is unable to establish direct clinical contact with them and day-to-day risk cannot be ascertained, medical responsibility should be transferred back to the GP with routine access to 24-hour out-of-hours care as needed.
- If a child or young person is referred back to the GP, and should they need to be referred for treatment again, the referral pathway is structured to allow rapid re-engagement.
- Reasons for cancellation or non-attendance are complex. In a system that tries to treat all children and young people, it is important that children, young people and their parents/carers are not left to re-book appointments without this being brought to the GP's attention.

3.2.6 Managing complex cases

The treatment of eating disorders in children and young people is often not straightforward for families, carers or clinicians.

If, following progress reviews, treatment is considered to be 'stuck' or other difficulties have arisen that the treating team are unable to readily resolve, clinicians should ensure that they approach the child or young person and their parents or carers and discuss consultation with other colleagues. Ideally, eating disorder service teams will form peer networks for this purpose.

Effective working and the relationship between the individual seeking help, the family or carer and the clinician is key to recovery. One of the guiding principles of the Eating Disorder NICE guideline (2004) is that families and carers should be involved in treatment and thus it is important to make every effort to maintain positive relationships not just within the family, but also between the family or carer and the treatment team, see Appendix C for guidance on information sharing. Clinicians should understand the strain the families or carers are under and that it is natural that at times a loss of confidence in the treatment team may occur. Clinicians should work with the individuals and their families or carers to amend the treatment plan and look at alternatives, perhaps through second opinions. Given the paucity of evidence in this area, clinical expertise is required to tailor treatment to the needs and preferences of the child or young person and their family or carer. The CEDS-CYP have agreed protocols to involve specialist services if other options are unsuitable and these protocols should be followed.

A carer's perspective

I carry on with my life now, but with 'contingency' planning. And I carry a lot of sadness and anxiety. As a mum, however I rationalise her illness behaviours, they still hurt. I grieve for the daughter I've lost.

3.2.7 Clock stops and treatment starts

Although the clock stops when the child or young person starts a NICE-concordant treatment package (that is, when the first session of NICE-concordant treatment is delivered), this is the start of the next stage of care. Service provision is monitored from this point on by the collection and submission of a variety of data connected to treatment, clinical outcomes and service user and carer experiences.

3.2.8 Outcome measurement

Eating disorder services need to collect a range of information in order to guide treatment and improve outcomes, capture service activities as well as enable children and young people and their parents or carers to inform service delivery and design. This information should include long-term follow-up measures and over time, this will evidence long-term outcomes.

Currently, however, data collection is poor due to high demands on clinicians, and incomplete and inconsistent reporting from services. There is considerable variation across CAMHS in the amount of resources committed to the development, implementation and monitoring of effective practice and outcomes (Child and Adolescent Mental Health Services, 2008).

In addition, there are particular difficulties with reliably and accurately capturing relevant outcome variables in child and adolescent eating disorders. These are complex, multi-factorial disorders, which represent significant challenges in relation to tracking meaningful outcomes. This is part due to an absence of appropriate self-report measures for some age groups, for example children under the age of 13. A number of other outcome parameters have variable significance for specific individuals (for example, percentage median BMI). It is recommended that healthcare professionals use their clinical judgement and use or tailor measures recommended from other age groups rather than not gathering any outcome data.

Appendix B details what data should be collected and how. It summarises key questions aimed at ensuring that outcome measures are used to ensure and monitor the engagement of the child or young person from assessment through to close of treatment. They are intended to:

- support a collaborative and person-centred approach to treatment
- ensure that the child or young person’s needs are being met
- ensure that the child or young person’s experiences are understood.

Data items will need to be collected for the MHSDS, details on these will be published shortly. See Appendix D.1 for an interim guide to the SNOMED measures.

4 Elements of a community-based eating disorder service for children and young people

4.1 Description

In order to provide a viable, community-based eating disorder service, the workforce needs not only to provide key capabilities, but also to be trained to deliver an evidence-based service to a high standard. Experience suggests that larger teams are more resilient and able to manage team losses without as great a risk of compromising services provided as may be the case for smaller teams.

CEDS-CYP requirements in terms of workforce, skills, competencies and training are set out below. These represent required standards for commissioned CEDS-CYP services.

4.2 Recommended approaches to service structure

Commissioners will need to consider the following when commissioning an eating disorder team or ensuring an existing service is ready to meet the Access and Waiting Time Standard when it is implemented:

- size of the population served by the team
- local incidence of eating disorders in children and young people drawn from the JSNA in Mental Health
- general level of coexisting mental health problems and how these will be managed
- capacity and effectiveness of current services
- anticipated impact of new or proposed services in meeting the need
- a model that will be able to achieve the waiting times for the anticipated level of need.

With this information and the CEDS-CYP workforce calculator, commissioners will be able to identify the size of the resource required to offer community-based treatment and meet the Access and Waiting Time Standard set out in this guide. The requirements for a CEDS-CYP are outlined in Section 2.6.1 above, with the size of the team dictated by the outcome of a needs assessment.

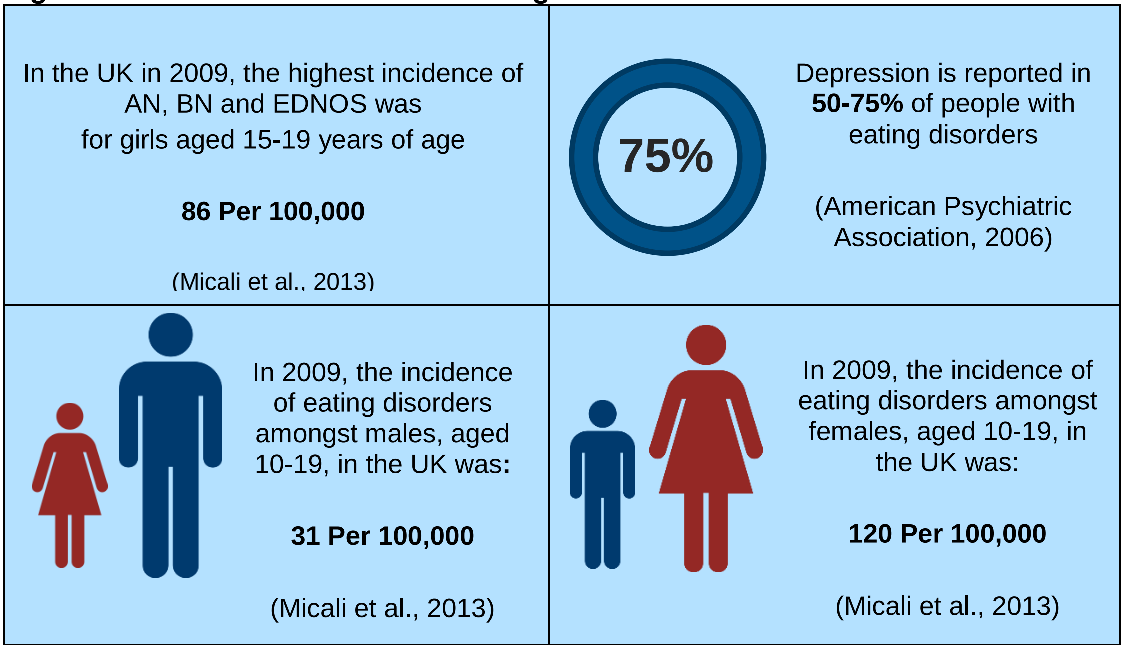


Figure 6: Estimated incidence of eating disorders

In the UK in 2009, the highest incidence of AN, BN and EDNOS was for girls aged 15-19 years of age **86 Per 100,000** (Micali et al., 2013)	75% Depression is reported in **50-75%** of people with eating disorders (American Psychiatric Association, 2006)
In 2009, the incidence of eating disorders amongst males, aged 10-19, in the UK was: **31 Per 100,000** (Micali et al., 2013)	In 2009, the incidence of eating disorders amongst females, aged 10-19, in the UK was: **120 Per 100,000** (Micali et al., 2013)

To create a viable team that can cover *the minimum recommended 500,000 (all age) population* commissioners will need to decide whether to commission a service for a single CCG or share the commissioning with other CCGs, and how the service will be delivered geographically. The balance between anticipated need, service size/cost, access and waiting times, and available funding will need to be achieved through a shared and agreed strategy among all partners involved.

If 2 or more CCGs are to share a service, then a 'lead' CCG needs to be identified and a shared agreement created on what will be commissioned and how the contract will be managed.

The models in Table 3 are possible options for structuring the CEDS-CYP. Both will provide a dedicated multidisciplinary community-based service that has the capability to treat the most common coexisting mental health problems:

Table 3: Models for structuring the CEDS-CYP

Model A	**Model B**
A single team based together that provides the entire service.	A team that operates via a network of smaller teams of eating disorder clinicians in neighbouring areas, via a hub and spoke model.

In both models, the teams must provide the capacity to meet all the needs anticipated in each of the CCGs commissioning the service. The service specifications for eating disorders and paediatric services will need to be interlinked to reflect the joint working between the 2 services. A paediatric liaison service for eating disorders should be included in the service specification for the eating disorder service or as part of a paediatric service specification.

4.3 Recommended approaches to workforce development

4.3.1 Competencies

All members of the eating disorder team should be competent in assessing and/or treating eating disorders. Different team members will be required to contribute different skills consistent with their professional training and further eating disorder specific training.

The inherent vulnerability of small teams has been recognised and care should be taken to protect against the loss of team members. A recommended way is to commission a community-based team with a staff group large enough to deal with this threat and with potential fluctuations in demand.

Each member of the team should have an appropriate qualification to deliver the NICE-concordant mode of therapy they are offering. Supervision from appropriately qualified supervisors must be maintained.

Each member of the team should have experience in:

- the treatment or assessment of eating disorders (flexibility will be needed when employing junior staff where training is needed)
- the mental health sector.

A professional's perspective

Supporting [children and young people] with [eating disorders] is emotionally…. It is important [that mental health professionals] seek regular supervision in order to remain compassionate, caring and optimistic.

The team's collective membership needs to provide the following expertise:

- psychiatric assessment for children and young people
- medical assessment and monitoring
- rapid response to referrals as outlined in the care pathway
- staff trained to supervisory level for evidence-based psychological interventions for eating disorders (to include CBT/CBT-E and targeted family interventions)
- staff trained in the delivery of evidence-based psychological interventions for eating disorders (to include CBT/CBT-E and targeted family interventions)
- community care: the team should have the experience to be able to provide home treatment and family support
- acute service and paediatric support: support should be provided to these services 7 days a week
- delivery of care: services should consider how they can provide care and response over a 7-day week
- administration: the team should have sufficient staff to provide administrative and management support; it is important to ensure that support staff are experienced and have adequate training in relevant areas including data entry.

The number of professionals within the team will depend on the anticipated needs of children and young people, and their families or carers within the geographical area served by the team.

4.3.2 Disciplines

A CEDS-CYP should be a multidisciplinary team of medical and non-medical staff with significant training and experience in the assessment, risk management and treatment of children and young people with anorexia nervosa, bulimia nervosa and their variants. These teams require a high level of expertise (both medical and non-medical) to be able to manage the level of medical risk safely and to provide continuous high-quality supervision for the psychological treatments.

These teams may typically include professionals from the following fields:

- clinical psychology
- dietetics
- family therapy
- nursing
- paediatrics
- psychiatry.

4.3.3 Staffing

There are many variables that need to be evaluated when building a CEDS-CYP team to meet the requirements outlined in this guide. The staffing levels and team make-up will vary across the country. It is expected that additional funding will be used to build either new teams and services, or be used to build upon existing community based services that are either already compliant or where the funding is being used to ensure compliance, with the model outlined herein.

The workforce mix and skills mix with whole time equivalent (WTE) staff in Table 4 and Table 5 have been calculated using data from recommended, well-resourced services that are currently providing community-based eating disorder services. This team configuration is an example of how a community based eating disorder service could be staffed, but actually staffing levels and skills mix will depend on the detailed requirements of the local service. Commissioners and service providers must ensure that local data collected during the needs assessment is used when calculating the workforce required for a CEDS-CYP.

Table 4: Whole time equivalent staff broken down by profession

Number of referrals per annum	**150**	**100**	**50**
		Whole time equivalents	
Head of service (psychiatry/psychology)	1.8	1.2	0.6
Speciality Doctors (psychiatry) (Registrars)	2.4	1.6	0.8
Paediatric medical treatment (Consultant)	0.3	0.2	0.1
Senior Clinical Staff (Bands 8a and 8b)	2.5	1.7	1.3
Eating disorder therapists (Band 7)	10.1	6.7	3.4
Home treatment specialists (Band 6)	3.8	2.5	1.3
Dieticians (Band 6)	2.3	1.5	0.8
Support Staff/Assistant Psychologists (Band 4)	2.7	1.8	0.9

Table 5: Whole time equivalent staff from Table 4 presented by role

Number of referrals per annum	**150**	**100**	**50**
		Whole time equivalents	
Therapists	16.8	11.2	5.6
Supervisors	4.8	1.6	0.8
Dietician	4.8	1.6	0.8
Medical	6.0	3.0	1.5
Administrative staff	7.8	2.6	1.3

Figure 7 and Figure 8 depicts the mix of skills needed in the team and an approximate mix of staff by grade. These numbers will vary for each CEDS-CYP depending on local need.

Figure 7: Staffing percentages by role

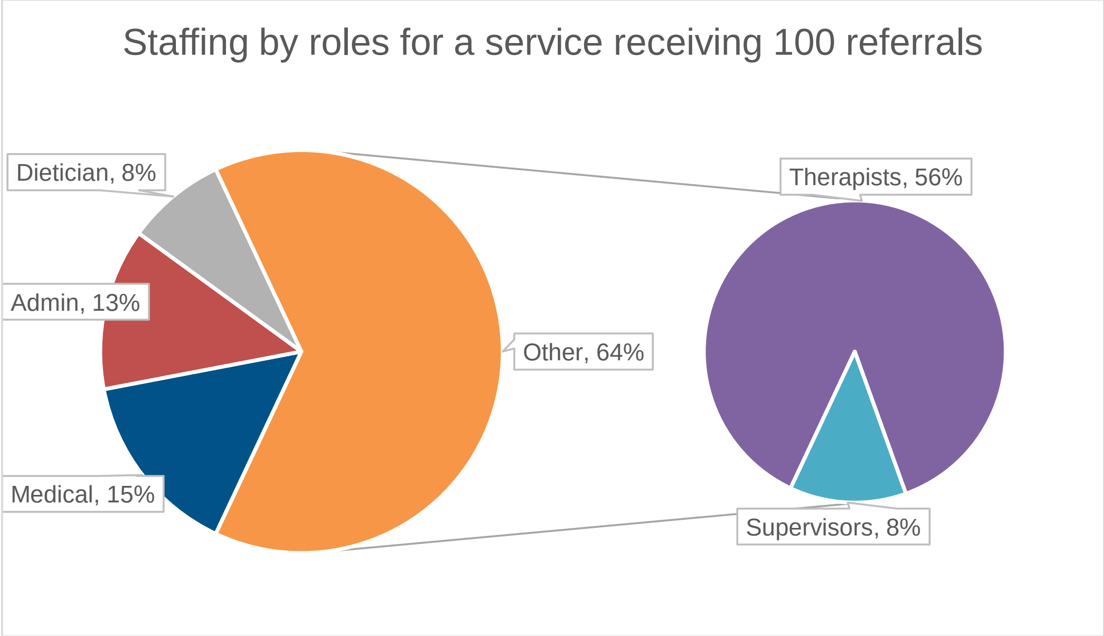
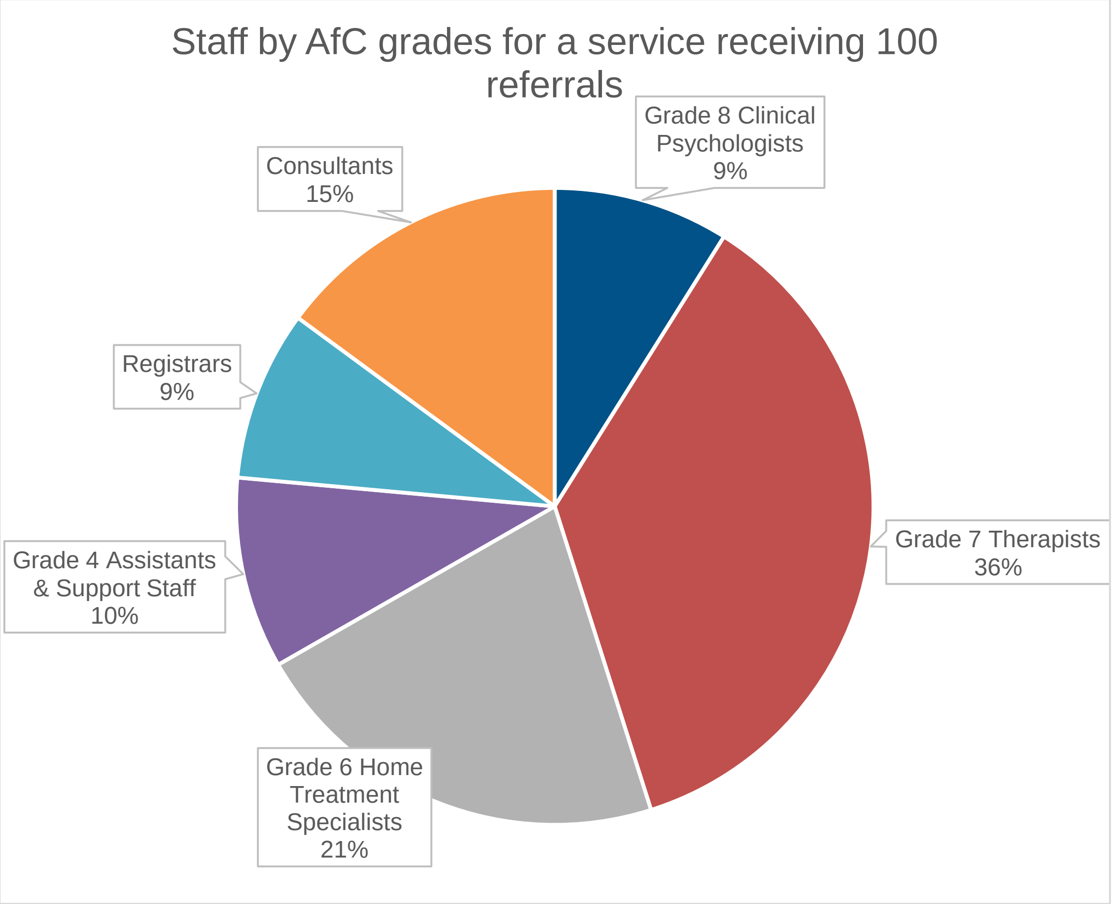


Figure 8: Staff by AfC grade



See Appendix F for a suggested CEDS-CYP workforce calculator. Please note that while this tool provides users with the ability to input a number of variables this is not an exhaustive list of the variety of possible inputs needed when calculating the workforce needed. To build a CEDS-CYP, commissioners will need to take into account local variables and other factors that will affect the service. Additionally, the mix of staff required by a CEDS-CYP will depend on the specific roles that they perform within the team (for example, interventions can be delivered by staff at different levels, with different titles and with different training). The calculator is therefore provided as an aid to discussion around need, and commissioners and providers will need to work together to establish the correct mix of skills and staff required to meet the Standard.

4.3.4 Staffing and overhead costs

Table 6 shows the costs based on the staffing described in Table 4 and the costs outlined in the PSSRU unit costs for health and social care for 2013–14, uplifted for 2013–14.

The costs below are based upon a staffing mix formula created in conjunction with current recommended services. The costs will change depending on individual service arrangements. See Appendix H for a full breakdown of PSSRU costs and the PSSRU website for additional information.

Table 6: Estimated recurrent cost for CEDS-CYP service/team

	150 referrals for min pop of 1,500,000	**100 referrals for min pop of 1,000,000**	**50 referrals for min pop 500,000**
Cost per service	£2,336,367	£1,559,061	£781,756
Note: The cost for referrals of £15,000 (for 100 referrals) is not the cost for a single patient, it includes a share of the steady caseload for the service.			

The key assumptions and caveats on this estimate are:

- It is based on clinical advice that the team specified in Table 4 will be able to meet the waiting time standard and manage existing caseload for 100 referrals a year
- There is reasonable evidence of the incidence of eating disorders, but much less evidence of the proportion of incidence which will lead to a referral to community eating disorder services. Estimates of this conversion rate in the literature range from 20–70%. We have assumed 50% of incidence will seek treatment to produce the costing above
- We do not have good information on what is currently spent on eating disorder services in the NHS, nor on what waiting times are being achieved, so this estimate assumes that the full recurrent cost of the service must be met from additional investment. We will begin to receive data on waiting times from January 2016 when the Mental Health Services Data Set begins to flow.

4.4 Recommended training approaches for all staff supporting children and young people with eating disorders

4.4.1 Training for members of CEDS-CYP

Eating disorder staff may need comprehensive training to improve skills. Overall goals of training to develop CEDS-CYP are included in Table 7.

Table 7: Training goals for a CEDS-CYP

Training goal	Detail
Develop multidisciplinary eating disorder teams	The aim is to create a multidisciplinary team that works together effectively. This can be best achieved by training professionals from different disciplines together as a team, rather than separately.
Understand the complex nature of eating disorders	The multidisciplinary eating disorder team should have knowledge of the epidemiology of eating disorders, risk factors predisposing people to develop the illness, physiological effects of malnutrition, physical and medical risks of starvation, and nutrition. The team should also understand that eating disorders commonly coexist with a range of mental and physical health problems, there is a high risk of self-harm, and that the needs of children and young people with an eating disorder and their families and carers vary considerably.
Develop a strong team culture	The most effective way to disseminate evidence-based practice (Greenhalgh et al., 2004) is to build on the team's existing knowledge and skills. This maximises learning by enabling team members to share their learning and support each other and helps teams to accept evidence-based practice. A strong team culture with shared values about the importance of evidence-based and outcome-focused practice makes it easier to manage transitions when members of a team leave and new members start.
Develop early intensive skills training and support and supervision	The structure of training should reflect evidence from dissemination research, which demonstrates the importance of early skills development to enable changes in practice and also continuous support and supervision (from within the team and outside the team) to sustain such changes (Stirman et al., 2004).
Adopt core CYP IAPT principles	Training for CEDS-CYP should draw on the principles and values outlined in Delivering with and Delivering Well, and the experience and expertise of the CYP IAPT programme in transforming services through training. This should include involving children and young people and their families and carers in developing shared treatment goals and in outcome monitoring.
Evaluate the impact of training on transformation of services	The development of new services and training of multidisciplinary eating disorder teams provides an opportunity to evaluate the impact of the investment of new funds on outcomes for children and young people with eating disorders.

As part of the CYP IAPT service transformation programme, NHS England is promoting the development of skills in the assessment and treatment of eating disorders. Staff in participating CAMHS partnerships can attend training in systemic family practice specifically for the treatment of eating disorders. To be eligible for this training staff should be members of a community-based eating disorder service that includes both medical and non-medical staff.

In 2015/16 the CYP IAPT programme will extend its curricula to support training of staff to meet the needs of children and young people with an eating disorder when delivering the therapeutic modality they are trained to offer (for example, CBT and family therapy for treating eating disorders).

Good collaboration and communication between services throughout the care pathway for eating disorders (including educational establishments) is paramount and only in this way can a properly integrated model of care be supported.

To achieve a transformation all staff will need to be involved in changing practice. This should involve ‘whole team’ training events and training for managers and supervisors as well as practitioners.

4.4.2 The role of CEDS-CYP in training for other professionals

Raising the awareness of professionals in primary care, education and other children’s services will improve early identification of children and young people at risk of developing or experiencing an eating disorder. When taking a pragmatic approach, there is a view that community-based teams are in a good position to provide training on awareness raising and signposting to professional groups working with children and young people.

The CEDS-CYP’s ability to deliver this training will need to be built into the planned workload and therefore impact on the size of the team.

The expertise from the CEDS-CYP can be used to support primary care, non-eating disorder specialist services, education, social care, public health and other agencies to work in partnership. The relationships developed through the training can be used to provide regular support to the teams involved in improving early identification of children and young people at risk of developing an eating disorder. This should lead to a truly integrated approach.

4.4.3 The role of public health

Public health professionals with the support of CEDS-CYP can best deliver raising awareness of children, young people, parents and carers about eating disorders. It is recommended that websites and helplines ensure that information on NHS services and other providers is accessible and up-to-date. This awareness raising will need to be delivered so that the messages are culturally acceptable to the populations covered in their local catchment areas.

Adults working in universal, targeted and specialist settings including CAMHS need to be aware of eating disorders. In March 2015, the Department for Education commissioned MindEd to work with parents and carers and co-produce e-learning sessions specifically to meet their needs for information and support.

5 How the Access and Waiting Time Standard for Eating Disorders will be measured

5.1 Quality improvement networks

The NCCMH has commissioned the CCQI to implement a quality improvement network to support the Access and Waiting Time Standard for Children and Young People with an Eating Disorder and the quality of care delivered by community eating disorder services.

The quality improvement network is aimed at raising standards of care that people with mental health needs receive by helping providers, users and commissioners of services assess and increase the quality of care they provide.

Using national clinical audits, surveys and peer-review visits, the CCQI will collect and centralise information from children and young people, parents and carers and staff about standards of care, thus improving accessibility and validity of data.

Commissioners will be provided with:

- a quality improvement network that helps clinical teams to support and learn from each other
- a peer-accreditation process that gives children and young people and their families or carers, commissioners and regulatory authorities confidence that teams are providing high-quality services
- launch events to encourage networking amongst clinicians
- up-to-date information on the quality of service they provide measured against CCQI standards which can be used to compare against national benchmarking data
- supported participation in clinical audit.

Service specifications should anticipate providers joining an appropriate quality network and could include Commissioning for Quality and Innovation (CQUIN) payment frameworks for delivering the Access and Waiting Time Standards.

5.2 Accreditation

The quality improvement network will offer accreditation. Mechanisms and criteria for an accreditation system for eating disorder services for children and young people are currently being developed by NCCMH in conjunction with the CCQI. The process of developing the accreditation system will involve consultations with all stakeholders including children, young people, parents, carers and professionals. This system is due to be launched in the spring of 2016.

Robust processes will need to be in place to gather relevant data on achievement of the Access and Waiting Time Standard, delivery of NICE-concordant treatment and outcome measurement that will be used for accreditation purposes.

The scheme will assess a variety of features of eating disorder services across the country. These will include, but may not be limited to:

- successful delivery of NICE-concordant treatment within the Access and Waiting Time Standards outlined in this guide
- the ability of the service to adhere to the referral to treatment times outlined in this guide

- the capacity of the service to deliver evidence-based treatment
- provision and uptake of education and training across the care pathway
- the routine collection of and response to outcome data.

The aim of the scheme is to encourage services to improve provision and performance. The scheme will be underpinned by an external peer review system. The results of the accreditation programme will be published.

5.3 Mental Health Services Data Set

The current Mental Health and Learning Disabilities Data Set (MHLDDS) v1.1 and CAMHS v2.0 (which integrates CAMHS v1.0 and CYP IAPT) data sets have been combined to form the new Mental Health Services Data Set (MHSDS). This new data set includes the specifications for the use of providers of eating disorder services to measure outcomes for the assessment and treatment children and young people. Providers are expected to begin collecting the relevant data no later than 1 January 2016.

Publication of the Information Standards Notice (which mandates the NHS and system suppliers to make the relevant changes) and all supporting documentation including the technical specification and related guidance can be found at the HSCIC website.

6 Steps to commissioning a service that meets the Access and Waiting Time Standard for Children and Young People with an Eating Disorder

6.1 Introduction

The Access and Waiting Time Standard requirements must be adopted by all eating disorder services and this will require a transformational approach by commissioners. The creation or increase in the capacity of CEDS-CYP is central to improving outcomes, however this alone will not achieve the desired transformation. The following section is a practical guide outlining what is expected from commissioners in order to prepare for implementing the Access and Waiting Time Standard and address the challenges associated with current service delivery (see Section 2.4.2). NHS England has published resources and a checklist is provided in Appendix F as an aid to ensure commissioners are prepared for transforming their services.

It is important that the commissioning of eating disorder services complies with the principles and values laid out in Delivering with and Delivering Well. These principles are embedded in established accreditation and quality improvement networks for CAMHS, and will form part of the standards for accrediting a CEDS-CYP.

Improving access and waiting times for eating disorder services will be best achieved within a wider joint CAMH strategy. This will require commissioners coming together to agree a shared commissioning process and strategy and all providers of children's services to understand the issues and how they should contribute to improving outcomes across the whole pathway.

6.2 Overarching principles for service design and development

The local Health and Wellbeing Board's JSNA and the Joint Health and Wellbeing Strategy, alongside a local equalities and health inequalities analysis, should be the key drivers for establishing the quality of service provision. Health and Wellbeing Boards, supported by the local government-led Health and Wellbeing System Improvement Programme and Public Health England, should ensure that both the JSNA and the Joint Health and Wellbeing Strategy address children and young people's needs effectively and comprehensively. Commissioners can find information and support for health and wellbeing system improvement at the Local Government Association website.

The additional funding as announced in The Autumn Statement 2014 is to improve services for children and young people under the age of 18. Commissioners may wish to commission services for children and young people jointly with adults, but in so doing should ensure that the current and new funds meet the needs of children and young people and that the funding for over 18s is supported by the adult mental health budget.

Commissioners should ensure that their *Transformation Plans* show a clear demonstration of their commitment to:

- service transformation
- transparency

- meeting legal duties with regard to equality, health inequalities and monitoring improvement; this can be achieved by:
    - commissioners and providers identifying the ethnic groups that may have potential need for the service, including those who may be experiencing barriers to access, and ensuring that services are readily available
    - all staff being appropriately trained in meeting the needs of diverse cultures and ethnic groups
    - all staff being appropriately trained in meeting appropriate legal requirements associated with information sharing and capacity, see Appendix C
    - commissioners and providers ensuring that all service provision is age-appropriate and gender-appropriate
    - ensuring that service provision is commissioned across the full range of complexity (to include clinical presentations that may be relatively rare, for example very young patients (aged 8–10) or those with specific significant co-occurring medical conditions.

The reduction of inequalities in access and outcomes is central to the transformation of services. Local commissioners are reminded that they should make explicit in their plans how they have taken into account the duties placed on them under the Equality Act 2010 and with regard to reducing health inequalities, duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities.

The focus of commissioning is the service user and the public, as outlined in Liberating the NHS: No decision about me, without me. Improving outcomes and creating an effective service model depends upon the involvement of children and young people and their families and carers in the commissioning process. Useful resources include:

- Model Specification for Child and Adolescent Mental Health Services: Targeted and Specialist levels (Tiers 2/3)
- Commissioning tools published for transitions from Child and Adolescent Mental Health Services (CAMHS)
- CAMHS Payment System Project.

6.3 Create a baseline assessment of current service provision

A baseline assessment must be completed so that best practice is maintained and services can be measured over the period of any new contracts awarded.

Commissioners will need to ascertain through their contracts and service specifications how eating disorder services are currently provided and if they meet the Access and Waiting Time Standard. The baseline assessment must include current service model, the number of WTE staff, skill mix and competencies in the service. This will be used to show how additional funding has been deployed to meet the Access and Waiting Time Standard and improve outcomes.

6.4 Understand local need

An assessment of local need that involves children and young people with eating disorders, and their families and carers, should be undertaken. Their engagement in assessing need, reviewing current services, deciding priorities and designing services will enhance the commissioning process and achieve the transformation required before deciding on the most effective procurement process.

To ensure that service user choice is embedded in the service specification, questions about where, when and how a service is delivered should be included in the review process.

The assessment should:

- predict the numbers of children and young people in need of support
- include children and young people being managed in primary care or schools, those requiring community support and those in need of risk management or urgent help and those who might need to access highly specialist care
- include a commitment to coherency with a wider CAMHS assessment of need
- include a gap analysis.

Commissioners should ensure that they incorporate a range of demographic features, such as ethnicity, age, population density and deprivation in their eating disorders needs assessment.

Prevalence data should be applied to population data, however, this is not always sufficient as it is not a good predictor of need on its own. Providers need to be aware of any previous ‘seasonal’ variations and plan accordingly so that waiting times can still be met during times of high referral rates. Referral rates and number of expected number of children and young people requiring assessment, support and treatment should be used in the workload predictions.

6.5 Establish protocols to support the pathway

The Child and Adolescent Mental Health Services (CAMHS) Tier 4 Report on eating disorders (July 2014) highlighted the need for the development of community-based eating disorder services to reduce the need for admission and to improve service user outcomes (CAMHS Tier 4 Report Steering Group, 2014). In developing the service model, it is essential:

- eating disorder services for children and young people are able to meet the Access and Waiting Time Standard
- children and young people with an eating disorder are able to access NICE-concordant treatment at every stage of the care pathway.

Commissioners need to ensure that there are clear self-referral routes into the CEDS-CYP, including a communication plan to ensure children and young people, their families and carers and other professionals are aware of how to access services. Commissioners can use the additional funding to develop or enhance community-based eating disorder services to improve access and meet the needs of children and young people in the population covered.

In some circumstances, primary care is capable of providing good outpatient support for children and young people with a manageable eating disorder. Where this happens, GPs and associated practitioners need to be appropriately trained and supported in both child mental health care as well as eating disorder treatment by the CEDS-CYP. Once a primary care practitioner has been identified as having the appropriate training to provide community care they should register this with the CEDS-CYP to receive support and, where appropriate, supervision. There must be a clear agreement that the CEDS-CYP will have oversight of all eating disorder cases and provide case supervision to those being managed in primary care.

The CAMHS Tier 4 Report also noted geographical variability in the development of eating disorder services, which has been largely provider driven. The report suggested that further work is needed to clarify the role and remit of inpatient care. Commissioners need to show a clear demonstration of their commitment to reducing out-of-area care, including ensuring inpatient beds are located as close to home as possible. The evidence shows that early identification and treatment of eating disorders leads to a shorter recovery time and fewer relapses. Although there are a number of complex cases that cannot be effectively dealt with by current community-based teams and specialist services should be involved for such cases, with the improvement of early identification and intervention it is anticipated that the number and severity of these complex cases will decrease. However, in the meantime it is important that commissioners ensure that children and young people have access to appropriate services to improve outcomes and reduce relapse risk. Commissioners must get the balance right between supporting the severely ill while also delivering preventative work that will reduce the demand for more intensive care.

It is known that there are current pressures for CAMHS beds. NHS England has worked with providers to increase capacity and improve the systems that support accessing these beds. It is envisaged that any reduction in demand for the current beds will create capacity in system to allow improved flow of patients through the system to support the most appropriate timely treatment.

6.6 Establish liaison protocols

Commissioners must create a balanced service provision across a range of needs and in order to do this collaborative commissioning with schools, the local authority and NHS England is essential.

If the transformation is to be successful it will require primary care staff and schools to be aware of the issues for children and young people with an eating disorder (for example, early identification and support can reduce recovery times) and provide early support or signposting services. It is therefore important that commissioners of primary care services in NHS England, local authorities (health visiting, school nursing) and schools are involved in the transformation of eating disorder services from the outset.

Liaison with paediatrics

The provision of paediatric care must be included in planning and delivery of the CEDS-CYP and liaison with paediatric (to include general paediatrics, endocrinology, gastroenterology and other specialities as required) and other child health services (for example, primary care and dietetics) is essential. Paediatric services have a central role in the care of children and young people with eating disorders, not just in acute situations but also in specific high-risk groups (for example, those going through puberty and those with coexisting diabetes).

Liaison with inpatient services

The effectiveness of community-based services will affect the need for inpatient services for children and young people with an eating disorder. Local acute commissioners of paediatric inpatients and NHS England commissioners of inpatient services will therefore need to be involved in the local strategy for eating disorders, which should in time lead to planned reduction in demand.

The CEDS-CYP should have a strong link with inpatient services, the purpose of which will be to allow for brief admissions, with subsequent care to be delivered by the CEDS-CYP. This can be done either with a link to a CAMHS Tier 4 unit or paediatric hospital. Commissioners are aiming to improve outcomes and reduce travelling by establishing these links.

6.7 Create a workforce

6.7.1 Planning

The CEDS-CYP required to provide the breadth of services described in Section 4 will need to be of sufficient size to manage staff turnover and ensure the variety of evidence-based treatments are always available. Current practice suggests that a CEDS-CYP will generally be effective if it serves a population of at least 500,000 people and receives a minimum of 50 new eating disorder referrals per year. This will mean that in most cases the service will need to be commissioned to cover 2 or more CCG areas, which will require joint commissioning.

Providers will be required to show they have sufficient staff trained in evidence-based treatments, collaborative practice and the use of outcome measures to meet the predicted need, or have a plan to develop the staff through a transformation programme.

The System Dynamic Service Modelling Tool, which is currently in development, will be a useful instrument that can help commissioners to understand staffing, skill mix and workforce requirements for their services, based on the level of need, incidence of eating disorders and demographics unique to each geographical area. A beta version of the modelling tool and the supporting ‘business guide’ is available via the CSU website at http://www.scwcsu.nhs.uk/camhs

6.7.2 Recruiting

Your *Transformation Plans* must include a recruitment and retention strategy.

6.7.3 Training

The demand for training from providers will be significant, regionally and nationally. Meeting the anticipated rise in demand for training can be best managed centrally, at this stage, through the development of a curriculum commissioned by Health Education England. This will meet the need for a rapid increase in professionals who can deliver evidence-based treatments and mandated outcome measures.

Commissioners can use funds to provide awareness raising and basic training for staff in children’s services and for families/carers, training and supervision of staff in evidence-based care, collaborative and outcome focused care. A robust training plan should be included in the *Transformation Plans*, and commissioners should demonstrate they have a programme to develop and maintain the skill mix required to deliver the service.

Commissioners should refer to the CYP IAPT curriculum for information on training therapists, supervisors and service managers.

6.8 Support transitions

The commissioning of integrated pathways is essential to reduce disruption during transition from child to adult services, and when a person is moving from one area to another or from one service to another. Commissioning arrangements rely upon NHS England and local CCGs working together. Guidance on commissioning for transitions and protocols to support the transfer of care between services has been published by NHS England.

Age-based transitions

It is important to jointly plan transitions from child to adult services with adult mental health commissioners. The decision about who should provide services for the young person after the age of 18 should be based on the needs and best interests of the young person.

Geographical transitions

Commissioners and providers should be aware of the particular issues that arise in providing a service to young people who have left home to study or have moved to a different geographical area. In this situation there should be careful consideration involving all parties as to where treatment would be best provided.

6.9 Establish data collection and outcome measurement protocols

6.9.1 Outcome measurement plan and data collection

A service user's perspective

Counselling at my university was good as I didn't have to panic about whether funding would run out or the timescale to our working. I knew I had someone there to talk to at a pace that suited me.

During the design of the service, commissioners must prioritise the views of the child or young person. Commissioners must also involve children and young people and their families or carers in monitoring quality and outcomes because they frequently report being excluded from treatment and that their views are not being sought. The measures for children and young people with an eating disorder in the MHSDS are a minimum data collection requirement and locally agreed indicators can be added. The data provided should be used to inform future commissioning decisions.

The service specifications for NHS, local authority, voluntary sector and private providers should include processes to:

- support the completion of outcome measures by children and young people and their families and carers
- support the use of data collected during clinical sessions to improve treatment plans
- ensure that data collection meets the standards set out by the MHSDS (see Section 5.3)
- send the service development monitoring data to an outcomes support organisation, such as the Child Outcomes Research Consortium (CORC - see Section 6.9.2)
- outline how the data will be used to improve:
  - individual clinical practice and skills development
  - outcomes of individual children, young people and families
  - service quality
  - future commissioning.

There is a need for providers to be a member of a publicly transparent quality improvement network. The NCCMH has commissioned the CCQI to implement such a network (as described in Section 5) to support the Access and Waiting Time Standard. The aim is to support members in working together to deliver the best possible care for children and young people.

6.9.2 Development of an electronic care record system

Commissioners need to ensure providers prioritise the installation of the primary electronic care record system to enable clinicians to use outcome data systems to guide treatment. Ideally, children and young people should be able to access these systems in order to update their own data.

To help manage service provision each provider will need to purchase or develop an electronic care record system, which includes arrangements for sending the service development monitoring data to the commissioner, NHS England and a quality improvement network so that benchmarking can support the continued commissioning process.

CORC has valuable resources including information on establishing an outcome evaluation protocol, some of the systems available and pertinent questions to ask suppliers when selecting a system. CORC provide advice about how to choose between systems, but does not seek to promote any one system. Whichever system is chosen, it needs to support the collection of data that is required by the MHSDS and minimise the burden of double entry and the associated errors that accompany this practice.

6.9.3 Developing reports for testing performance

Commissioners and providers will need to develop and produce reports on outcome measures and service activity and agree how the data from the above reports can be best used to support service development and future commissioning.

6.10 Support your accreditation plans

The principles and values outlined in Delivering with and Delivering Well are embedded in established accreditation and quality improvement networks for CAMHS, and will form part of the standards for accrediting a CEDS-CYP in the future.

6.11 Create a benefits realisation plan

Commissioners should outline in their plans how the additional funding will transform services and lead to efficiencies and reinvestment. The benefits realisation plan should include information on how:

- early identification and NICE-concordant treatment will lead to shorter recovery periods and reduce relapses rates
- collaboration between CCGs, schools, the local authority and NHS England will reduce or streamline transitions across services
- community-based treatment will lead to reduced admissions to inpatient services and increase capacity.

7 Service examples of good practice

7.1 Introduction

The following community-based eating disorder services have been included in this guide in order to provide examples of how commissioning goals can be achieved in the real world. These specific services were chosen because each one demonstrates how the standards and principles of recommended practice outlined in this guide can be achieved, and how this results in a positive impact on outcomes for children and young people and their families and carers.

7.2 Cheshire and Merseyside Eating Disorder Service for Adolescents

The Cheshire and Merseyside Eating Disorder Service is a dedicated community eating disorder service that was established through a partnership with the University of Liverpool research team, following a successful National Institute for Health Research (NIHR) Health Technology Assessment (HTA)-funded treatment trial. They cover an overall population of approximately 758,000.

An audit of the service in 2008 showed that they received 83 referrals and accepted 59 for assessment; 52 of these new referrals went on to receive treatment. Out of the 52 who accepted treatment, 9 were offered admission. The audit recorded that 49.3% of the referrals came via GPs, although the service accepts referrals from a variety of sources (as recommended in Section 3.2, although they do not yet accept self-referrals).

The Cheshire and Merseyside Eating Disorder Service provides treatment packages on an outpatient and day patient basis, with a focus on community care that involves the family in all cases. Because of this service design, there has been a significant reduction in inpatient admissions and bed usage by young people with an eating disorder in the area, both within NHS Tier 4 CAMHS, and NHS-funded independent health services.

The service has demonstrated a commitment to involving families and carers in the treatment process, which is a component that has been shown to be valued by young people, parents and carers (as outlined in Section 3.5). The service has systematically conducted audits on the experience of young people and their families and carers at the end of treatment, and has looked at user satisfaction with the multi-family therapy groups they provide, with very positive results. Clinical outcomes are also reviewed and positive results have been published (APS Group Scotland, 2012) and an HTA monograph. The service has established a sound outcome evaluation protocol, as recommended in Section 3.2.8.

The service is dedicated to improving skills (as recommended in 4.3.4) and funding is provided for training of multidisciplinary teams alongside service provision. In addition, staff attend annual training conferences for Tier 3 CAMHS. They have established a dedicated multidisciplinary team, which includes 2 psychiatrists who lead the team, a specialist registrar, 2 clinical psychologists, therapists trained in a range of interventions and a dietician. The service employs 10 WTE clinical staff and has approximately 2 WTE support staff, which is broadly in line with the recommendations in 1.1.1.

7.3 Exeter, East and Mid Devon Child and Adolescent Services

This community eating disorder service, covers an overall population of approximately 760,000, has a multidisciplinary team that accepts approximately 100 referrals per annum. The service provides consultation and treatment for children and young people who are experiencing a range of severe and complex emotional and mental health problems (as recommended in 4.2). Just under a third (30%) of the children and young people who are referred to the eating disorder service require treatment for a coexisting mental health problem.

This service was one of the earliest adopters of the CYP IAPT transformation programme and provides a good example of how time and resources can be effectively allocated for staff training and service development, as recommended in Section 4.3.4. Through the CYP IAPT transformation programme, the service has trained staff in the delivery of systemic family practice for children and young people with an eating disorder. They have also trained systemic family therapist supervisors.

The team consists of 15.5 WTE clinical staff from a range of disciplines, including psychiatry, psychology, family therapy, dietetics and nursing. In addition, the service has 3 support workers who provide home treatment and community care, 2 members of staff dedicated to supporting those with coexisting mental health problems and 1 senior member of staff providing oversight and support to inpatient services. The mix of skills and staff numbers reflects the recommendations in 1.1.1 and allows the team to provide a service that has led to a reduction in the need for inpatient admissions to Tier 4 CAMHS.

This service also provides an excellent example of how partnerships with paediatric colleagues and services can be achieved in order to overcome some of the challenges outlined in Section 2.3. The team has established a strong link with a paediatrician at the Exeter and Devon Hospital with a specialist interest and expertise in eating disorders, which has had a dramatic impact on delivery of care.

The service has established an outcome measure protocol (in line with the recommendations in Section 3.2.8, which illustrates how eating disorder teams can use outcome data and service user feedback to help guide treatment and develop their practice. In addition to a successful feedback system, the service has developed an online reporting system for outcome data. This allows commissioners to easily access relevant and detailed information relating to targets and objectives.

7.4 Gloucestershire Eating Disorder Service

The Gloucestershire Eating Disorder Service provides community-based treatment for children and young people with complex eating disorders and covers a population of 860,000. As part of its service specification it aims to make available NICE-concordant treatment to all residents of every area covered by the trust (see Section 3.1), acute hospital care for physical conditions and a full range of mental health liaison services, as recommended in 4.2. Additionally they have a focus on prevention, especially early intervention (as required in Section 3.1.3). The service receives approximately 130 referrals per annum and has a clinical staff of approximately 23 WTE with additional supporting administrative staff (which is in line with the recommendations in 1.1.1).

There is an open access referral system (as recommended in 3.2.1) that increases the likelihood of people being able to access appropriate treatment that takes into account barriers (as described in 2.3) that might make compliance with treatment difficult. The service has a single point of contact for anyone coming into the service, demonstrating a commitment to ensuring open access to all children and young people and their families in line with the pathway and Access and Waiting Time Standard requirements outlined in Section 3.

The community-based nature of the service means that lengthy periods of disruption to education, work, family life and development due to hospitalisation are minimised, but when the physical health of the child or young person might be compromised, inpatient care is available as a last resort. The community team comprises 9.7 WTE staff.

A multidisciplinary team (5.5 WTE) that includes a consultant psychiatrist, therapist and dietician provides day treatment and home treatment is primarily given by 5 dedicated staff who also support the community team by providing 7 clinical hours per week. This innovative service design helps overcome the challenges of transitions, as outlined in Section 2.3. By employing a flexible approach to intensive outpatient working, the home treatment team can provide intensive, evidence-based treatment, meaning that the child or young person can remain in the family home as an alternative to hospital admission. The home treatment team has had a significant impact on service user outcomes and cost effectiveness, reducing the length of stay for inpatient admissions by half over a 3-year period. Despite overall reductions, there can at times be a spike in admissions which could be associated with improved identification or increased prevalence.

The service provides intensive support for children and young people and their families in their home, day treatment support for young people aged 16 and over, as well as a range of support groups for the children and young people and their parents, carers, siblings and friends, as recommended in Section 3.1.2. The support groups provide a safe place to receive additional support, alongside others who understand what it is like to live with an eating disorder.

In addition, the service has shown a strong commitment to the principles of training and supervision outlined in Section 4.3.4. Not only has the eating disorders team received training from external experts and regular supervision, they also provide training to professionals in primary care and in the public sector, including school nurses and teachers.

7.5 South London and Maudsley (SLaM) Child Adolescent Eating Disorders Service

SLaM Child and Adolescent Eating Disorders Service provides community-based eating disorder assessment, treatment and care for children and young people with severe physical and psychological problems relating to eating disorders. The service also provides an intensive day treatment service for children and young people with anorexia nervosa. The service covers a population of approximately 1.8 million people, which encompasses 7 boroughs in south London. It provides outpatient and day patient care, with the day programme additionally accessed by children and young people from boroughs in Kent and Surrey. The service receives 160 new referrals per year and has an active caseload of approximately 250 children and young people each year.

In 2014, SLaM began a 15 month pilot study in southeast London, to facilitate rapid assessment and flexible tailored treatment for young adults in the early stages of their illness. Information on FREED can be found on the SLaM website.

The service provides a good example of how CCGs can work collaboratively to commission services across large geographical areas in order to ensure equal access to a high-quality service for children and young people in areas with smaller population size, in line with recommendations in Section 4.2.

The impact of this community-based service has been recently audited; data shows that 80% of children and young people receiving this treatment are discharged having recovered from their eating disorder after an average of 1 year of treatment.

Alongside improved service user outcomes and lowered inpatient admission rates, the service has demonstrated a strong commitment to training and staff development, in line with the recommendations outlined in Section 4.3.4. The service aims to share its expertise through providing team-based training to other community eating disorder services covering evidence-based treatment modalities (such as eating disorder-focused family therapy, multi-family therapy, cognitive remediation therapy and CBT) as well as service model development and delivery.

7.6 Swindon, Wiltshire, Bath and North East Somerset Child and Adolescent Mental Health Service population

This CAMHS set up a community eating disorder service for children and young people 4 years ago. It consists of 4 clinics and comprises a number of multidisciplinary teams with bases in 5 areas covering Bath and North East Somerset and the whole of Wiltshire. This service provides a good example of how commissioners can work collaboratively across geographical areas in order to create viable, community-based eating disorder teams that meet the requirements outlined in Section 4.2.

Each clinic has 1 day a week of protected clinic time. Since December 2015, referrals have dramatically increased and the service currently accept 100 referrals per annum (in line with the CEDS-CYP requirements in Section 2.6.1). There are 100 children and young people in active treatment spread equally across the clinics.

Each clinic has a consultant child psychiatrist, a therapist and 1 other clinician and 3 clinics also have a psychologist on the team. Each clinic runs on 4 full-time clinical staff (12 across the service).

The service has shown a strong commitment to embedding the principles of CYP IAPT in their practice, in line with recommendations in Section 4.3.4. Almost all of their eating disorder clinicians have completed CYP IAPT training in systemic family practice, and many clinicians are also trained in CBT-E; all clinical staff are either CYP IAPT or Maudsley trained (see Section 4.3.4 for training principles that this service applies). The clinicians meet regularly for support and training and the whole team come together twice a year to ensure there is a consistency of treatment across the service. The service is looking to expand their therapy team by adding a clinician with multi-family therapy skills to their service.

The service established an outreach service for home treatment operating 7 days a week and assisting with home refeeding. As a result, admission rates for eating disorders are lower, both with regard to the frequency of inpatient admissions and length of stay (as a rule there are never more than 6 to 8 children or young people in hospital and usually much fewer). Given the success of the current team, the service is planning to expand the home treatment team and hire more community psychiatric nurses.

All children and young people are seen for assessment within 24 hours and those requiring acute service provision are assessed on the same day. Each dedicated eating disorder team within this service has established good links with paediatricians in their local areas and following Junior MARSIPAN guidance provides same day assessments. The service provides a 7-day service (as recommended in 3.1.3 for intensive paediatric support. They are able to admit children and young people to paediatric beds at local district general hospitals for short (1 to 3 week) periods of medical stabilisation where necessary. This service also offers a good example of how the challenge of inadequate liaison between healthcare providers outlined in Section 2.3 can be overcome.

The eating disorder teams have also embedded principles of CYP IAPT through the collection of eating disorder-specific routine outcome measures, in line with the recommendations outlined in Section 3.2.8. The services have recently established an eating disorder audit group to analyse these measures, which will enable them to monitor and evaluate the service and outcomes for children and young people. In an endeavour to improve their analytical capabilities, they are looking to expand the team and recruit a dedicated individual to perform research and analysis. This role will include reviewing the service and also the success of their outcome measurement collection in terms of validity of data (for example, the results of their recent adoption of the Eating Disorder Examination Questionnaire [EDE-Q] adapted for children under the age of 13).

8 Definition of terms and abbreviations

Table 8 lists the definitions used in this document.

Table 8: Definitions

Term	Definition
CAMHS partnerships	Local partnerships that bring together the organisations responsible for mental health services for children and young people and their families and carers in a shared commitment to improve mental health outcomes.
Child and Adolescent Mental Health Services (CAMHS)	Services that work with children and young people who have difficulties with their emotional or behavioural wellbeing.
Children and Young People’s Improving Access to Psychological Therapies (CYP IAPT)	A service transformation programme delivered by NHS England that aims to improve existing Child and Adolescent Mental Health Services working in the community.
Children’s services	Services that support and protect vulnerable children, young people, their families and young carers.
Children’s trust	Local partnerships that brings together the organisations responsible for services for children, young people and families and carers in a shared commitment to improving children’s lives.
Commissioning plan	A document that outlines the organisation, schedule, allocation of resources, and documentation requirements of the commissioning process.
Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5)	The American Psychiatric Association’s classification of mental disorder used by clinicians and researchers to diagnose.
Generic CAMHS	Targeted and specialist child and adolescent mental health services at tiers 2 and 3.
Health and Wellbeing Boards	Statutory bodies introduced in England under the Health and Social Care Act 2012. Each upper-tier local authority in England is required to form a Health and Wellbeing Board as a committee of that authority.
The Health and Wellbeing System Improvement Programme	An initiative to support and build leadership capacity within Health and Wellbeing Boards to enable them to implement the transformation agenda through the integration and reconfiguration of services. There is a range of support available, which is managed by the Local Government Association and funded by the Department of Health. This includes a self-assessment tool and opportunities for learning through LG Inform, Knowledge Hub, case studies and the electronic bulletin.
International Statistical Classification 11th Edition (ICD-11)	The World Health Organisation’s international classification of mental and behavioural disorders used by clinicians and researchers.
Joint CAMHS Strategy	A plan that sets out how services can work to meet the mental health needs of children and young people in an area.
Joint Health and Wellbeing Strategy	A document that sets out the priorities for collective action by local councillors, GPs and directors of Public Health, Adult and Children’s services.
Joint Strategic Needs Assessment	Assessments of the current and future health and social care needs of the local community, produced by Health and Wellbeing Boards, through which local councillors, GPs and directors of Public Health, Adult and Children’s services

	work together to understand and agree the needs of all local people.
Paediatric service specification	A statement of needs to be met by a paediatric service.
Service specification	A statement of commissioning needs to be satisfied by the procurement of external resources.
Targeted CAMHS team	A Targeted team provides services for children and young people with particular problems or for those requiring particular types of therapeutic interventions
Transformation Plans for Children and Young People's Mental Health and Wellbeing	As set out in Future in Mind these articulate local plans to deliver the national ambition to transform the design and delivery of a local offer of services for children and young people with mental health needs. The plans 'should cover the whole spectrum of services for children and young people's mental health and wellbeing from health promotion and prevention work, to support and interventions for children and young people who have existing or emerging mental health problems, as well as transitions between services' (Future in Mind, p. 18). Key elements of the Plan will include commitments to transparency, service transformation and monitoring improvement.

Abbreviations used in this document used in this document

Table 9 lists the abbreviations used in this document.

Table 9: Abbreviations

Abbreviation	Full term
AN	Anorexia nervosa
ARFID	Avoidant/restrictive food intake disorder
BN	Bulimia nervosa
BMI	body mass index
CAMH(S)	child and adolescent mental health (services)
CBT(-E)	cognitive behavioural therapy (enhanced)
CCG	clinical commissioning group
CCQI	Royal College of Psychiatrists' College Centre for Quality Improvement
CEDS-CYP	community-based eating disorder services for children and young people
CORC	Child Outcomes Research Consortium
CYP IAPT	Children and Young People's Improving Access to Psychological Therapies programme
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDNOS	eating disorder not otherwise specified
GP	general practitioner
ICD	International Classification of Diseases
MHSDS	Mental Health Services Data Set
NCCMH	National Collaborating Centre for Mental Health
NICE	National Institute for Health and Care Excellence
PROMS	Patient-reported outcome measures
PSSRU	Personal Social Services Research Unit
WTE	whole time equivalent

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Appendices

Appendix A: What are eating disorders?

A service user's perspective
A lot of my communication with others around me broke down. I didn't know how to communicate how I was feeling or explain anything to people who were oblivious to the [eating disorder].

Eating disorders are serious, often persistent, mental health disorders associated with high levels of impairment to everyday functioning and development, and a high burden on families and carers. They can be associated with life-long physical, psychological, educational and social impairment and in some cases can be fatal. The public often misunderstands eating disorders, for example, a common belief is that they are a lifestyle choice. It is essential that as a society, we address the lack of public understanding, improve early identification, and facilitate timely access to available, high-quality treatment. The aim is to militate against the damage these disorders can cause. It is particularly important that we treat children and young people swiftly and effectively and support their families throughout the process. This will help minimise the likelihood of longer-term difficulties and increased healthcare needs. It will lower the economic burden related to inadequately treated eating disorders, which includes increased inpatient care, long periods in community care, transition to adult eating disorder services, unemployment and financial burden to families in terms of time off work and travel costs.

Kayleigh's story

Kayleigh was the youngest of 4 children. Her mum and dad had separated by the time she was 3. She lived in a quiet suburb where people knew each other through school or afterschool activities. Despite occasional struggles like saving up for a family car or a holiday, life was fairly peaceful for Kayleigh. Through her early teens Kayleigh started experiencing symptoms of an eating disorder. Having always been a 'fussy eater' and of 'slim build', the catalyst for her downward spiral was the onset of depression which led her not to the help she needed, but to the underworld of pro-anorexia websites. Despite the bad press, Kayleigh suddenly felt part of a community. She was not encouraged to lose weight and found support from people who were experiencing the same thing; however qualified treatment and support were not available. The urge to control her food led to counting calories, hiding food and long battles with her mum who realised Kayleigh was not eating. At 16, after running away from school and attempting suicide, Kayleigh's school and GP referred Kayleigh to the local young adult mental health team. Kayleigh saw a social worker once a week who drove her around and talked, a psychiatrist prescribed medication and a dietician taught Kayleigh about food groups, but there was no eating disorder treatment. In the meantime, Kayleigh was fixated on losing weight and did not believe that anyone could help. Under threat of being sectioned, Kayleigh admitted herself as a day patient and her long battle with anorexia started. After 6 long years of failed suicide attempts and self-harming, the turning point for Kayleigh was going to university.

After attempting suicide the same night as a fellow student, Kayleigh survived, but the other student did not. Kayleigh realised that she wanted and deserved a life and that she had been given another chance. Kayleigh started recovery at her own pace and now campaigns for better mental health care. She believes that helping one person would make her struggle worthwhile.

Commentary: Although she is recovering now, the delay in qualified treatment has resulted in a substantial cost to Kayleigh and society. Could Kayleigh's distressing experiences have been prevented with earlier help from a qualified community team? Would an eating disorder team trained in treating both her eating disorder and her depression prevented further suffering and bought Kayleigh closer to recovery earlier?

In the UK, CAMH eating disorder services have typically provided input for children and young people with anorexia nervosa, bulimia nervosa and atypical forms of these disorders, to include in some instances those with binge eating disorder. The Eating Disorder NICE guideline (2004) reflects this, covering ‘anorexia nervosa, bulimia nervosa, binge eating disorder or other related (or ‘atypical’) eating disorders’. The NCCMH is currently updating the guideline and it is due to be published in 2017.

Eating disorders include serious life-threatening conditions with some of the highest mortality rates of any psychiatric disorder. They have a significant impact on children and young people with the disorder, and their parents, family and friends. In order to improve outcomes for children and young people and to reduce the personal burden of eating disorders, it is essential that commissioners first understand and fully appreciate the magnitude of this impact. Eating disorders also commonly coexist with a number of other mental health problems, including depression and anxiety disorders.

In order to understand better the impact of eating disorders on children and young people and their families and carers, we asked a number of service users, carers and mental health professionals about their experience of eating disorders. A number of consistent themes emerged from these discussions (such as the substantial impact that eating disorders can have on day-to-day life, emotional wellbeing, and interpersonal relationships); there are excerpts from these discussions in quotation boxes throughout this guide.

A service user’s perspective
[Having an eating disorder] means having an internal battle with your feelings, emotions and natural instincts every day. You feel like you are trapped within your own your mind. Issues around food, body image and food itself become so torturous you feel like there is

Anorexia nervosa

Anorexia nervosa is characterised by extreme restriction of food intake, resulting in low body weight. In children and young people, it can slow or halt growth and pubertal development. Despite being at a low weight, individuals with anorexia nervosa tend to experience fear of gaining weight or of becoming overweight. Consequently, excessive exercising, self-induced vomiting, misuse of laxatives, or other behaviours, with the intention of preventing weight gain, may accompany dietary restriction. People with anorexia nervosa often see themselves as larger or heavier than they really are and tend to judge their self-worth in terms of their own weight or shape. This can cause significant distress and contribute to restriction of food intake. Individuals with anorexia nervosa are often unable to recognise the extent of their low weight or the seriousness of their condition, which means they do not think they have a problem or need help. Long-term physical consequences can affect height, brain development and bone density. In a minority of cases, death occurs; most fatalities are due to the consequences of malnutrition or suicide.

A carer’s perspective

My daughter suffered unimaginable distress. Family, work, colleagues, neighbours, all were affected [by the eating disorder].

People with anorexia nervosa present in clinical settings from around the age of 8 years upwards. The majority of children and young people seen in clinics are female, with an estimated 10-20% being male (Muise et al., 2003). There is a critical window for intervention because recovery is less likely if the disorder has remained untreated or inadequately treated for more than 3 to 5 years (Von Holle et al., 2008).

Bulimia nervosa

Bulimia nervosa is characterised by 2 main types of behaviour: recurrent ‘binge eating’ and ‘compensatory’ behaviours. Binge eating refers to eating large amounts of food associated with an accompanying sense of lack of control. Compensatory behaviours are intended to militate against the consequences of overeating. They typically include ‘purging’ behaviours (self-induced vomiting and laxative misuse) but also dietary restriction, excessive exercising or misuse of other types of medication. Such behaviours can lead to serious physical problems, and in a few people can be fatal (most often caused by the consequences of purging behaviour or suicide). As with anorexia nervosa, people with bulimia nervosa tend to judge their self-worth in terms of their own body shape and weight. Body weight in people with bulimia nervosa tends to be in the normal range or above, and so the disorder is often less obvious than anorexia nervosa. Individuals with bulimia nervosa are often embarrassed and ashamed about their behaviour, which can lead to reluctance to seek help.

Bulimia has a slightly later typical age of onset than anorexia nervosa, with presentations to clinical settings from around the age of 12 or 13 upwards. Some people have anorexia nervosa before developing bulimia nervosa. The majority of children and young people with bulimia nervosa are female, with an estimated 5-15% being male (Muise et al., 2003).

Binge eating disorder

Binge eating disorder is characterised by recurrent binge eating, but without compensatory behaviours. Body weight is usually above the normal range. Binge eating is mostly solitary, often occurring in the absence of hunger and typically accompanied by feelings of shame or disgust. Individuals with binge eating disorder often experience marked distress about their behaviour.

Typical age of onset of binge eating disorder is generally thought to be in later adolescence or early adulthood, with the majority of people presenting later (that is, in their 30s or 40s) (see NICE, 2004). Therefore, prevalence rates for binge eating disorder in children and young people in the UK are unclear, as many CAMH services do not see people with this disorder. However, the prevalence of obesity is increasing in children and young people in the UK and the cost to the individual in terms of quality of life, and to NHS resources, is high (Wang et al., 2011).

‘Atypical’ eating disorders

Atypical eating disorders include presentations that do not meet full diagnostic criteria for anorexia nervosa or bulimia nervosa as well as other clinically significant presentations characterised by eating difficulties. These disorders can have serious physical complications and influence social and emotional development, academic functioning and family functioning. Their physical consequences can be as serious as those in anorexia nervosa and bulimia nervosa.

> ***A professional’s perspective***
> *Experiencing [an eating disorder involves] an acute level of emotional and psychological difficulty around food which severely impacts an individual’s level of functioning, on a social, psychological and physical level.*

Atypical eating disorders, which are ‘full’ eating disorders, should not be confused with ‘sub-clinical’ disorders, a term often used to describe less severe presentations not meeting threshold for a diagnosis. Atypical eating disorders represent the majority of presentations in children and young people. These include presentations that do not meet exact criteria for anorexia nervosa or bulimia nervosa, but share similar features in relation to weight and shape concerns (Lock, 2010). Alternatively, they meet criteria for avoidant/restrictive food intake disorder (ARFID).

ARFID is characterised by avoidant or restricted eating behaviours, in the absence of preoccupation with weight and/or shape. Body weight in people with avoidant/restrictive food intake disorder can be in the low, normal or above normal range. When associated with very low weight clinicians now recognise this form of restricted eating behaviour as distinct from anorexia nervosa. Underweight people with ARFID may present with similar physical consequences related to significant weight loss and malnutrition as those with anorexia nervosa.

ARFID was first included in DSM-5 (American Psychiatric Association, 2013) and is due to be included in ICD-11 (scheduled for publication in 2017). Its inclusion has resulted from growing evidence about ‘atypical’ eating disorders. People with ARFID are seen in child and adolescent and in adult services. Emerging evidence suggests around 10-20% of children and young people referred to child and adolescent eating disorder services have a diagnosis of ARFID with further epidemiological and treatment research in progress (Fisher et al., 2014; Nicely et al., 2014). The diagnostic landscape relating to eating disorders is therefore changing, with anticipated refinements in treatment recommendations as new evidence emerges.

Alice’s story

Alice grew up in South London and although her dad was unwell during her teenage years she was embraced by a loving family. At age 11 she won a scholarship to a single-sex private day school where she experienced emotional abuse at the hands of her fellow students and experienced 5 years of isolation. She had one best friend, but Alice did not have a healthy relationship with her friend’s mother. The day after her GCSE exams Alice went on hunger strike; she wanted those who had hurt her to see the damage they had done.

After starving herself for months, Alice was referred to a an eating disorder service, who saw her in October of the same year. Alice went through 2 medical stabilisation/emergency re-feeding inpatient admissions in the first 12 months of treatment, but was mostly treated in an intensive outpatient programme. Alice still feels that the team saved her life. Alice was discharged 3 years later, aged 19, physically and (almost) mentally recovered.

In this slightly vulnerable state, Alice took her AS exams, but on the first day, her best friend died. This brought back the torment she had experienced before her eating disorder treatment. She had no specialist supervision at this point and despite starting in a school she liked, making many friends and enjoying her social life, Alice fell back into anorexia. Alice wanted the life she had found and having experienced excellent care previously she desperately tried to refer herself for more treatment. Alice was told that she ‘wasn’t thin enough’.

Having been accepted into university in 2011 Alice followed her dream, however she was again underweight and experienced a prolonged infection. Forced to suspend her studies she came back to London, to be admitted now as an adult patient with the same trust and treated as an outpatient. Alice recovered, returned to university and has been eating disorder free ever since. Now 23, Alice is an aspiring journalist hoping to build a happy and successful life for herself. However, she will never forget her life from age 16-21 when it was dominated by anorexia nervosa.

Commentary: Alice received excellent care that focused on outpatient treatment. If given treatment when she asked for it would Alice have been left in such a vulnerable state when leaving home to study?

Appendix B: Outcome Measures

B.1 Why collect data?

Regular feedback about how the systematic development of CEDS-CYP is impacting on the outcomes for children and young people and their families and carers is essential to the success of the programme locally and nationally. It is important to monitor and ensure that all sectors of the populations are being served and are able to access the services that they need. The introduction of these measures is timely as the introduction of MHSDS is planned for implementation from January 2016.

The mixture of activity, outcomes and feedback from the child or young person and their family or carers will provide a quality framework to measure the success of the strategic plans to transform eating disorder services.

The data set can:

- enhance the individual therapy experience of children and young people and their families or carers
- support the development of each practitioner’s clinical skills and development
- support the development of teams/services.

Commissioners can use the data to:

- inform future needs assessments
- review service provision through benchmarking and volume of service required
- inform priorities in terms of the most effective services for the identified need
- inform the design of services that will provide the most effective use of resources to achieve the best outcomes
- manage contract performance
- receive children and young people’s feedback on service provision, which will enhance their choices.

Eating disorder services can use the data to inform and support the continuous improvement of services.

If the benefits of the data set are to be realised and the outcomes for children and young people and their families and carers improved, the individuals collecting the data will be required to understand the therapeutic advantages of the data and build this into their practice through regular feedback to teams.

B.2 Challenges in data collection and storage

The successful collection of data will rely heavily on clinicians understanding the benefits of using the data as part of the treatment they are providing, how it can help to achieve treatment goals and improve outcomes. In some cases, this will require significant investment by providers in training and development of the workforce as part of wider *Transformation Plans*.

The data collection will apply to all CAMHS not just eating disorder services. The data will need to be recorded electronically so that it can be used for the various purposes described above. Providers will need to consider if they will develop or procure a system that will meet the requirements to use the data with individual children and young people and their families and carers, clinicians, teams and services. The specification of the system will need to ensure the data requirements of the Mental Health Services Data Set (MHSDS) will be met.

Lessons can be learned from the development of systems within the CYP IAPT and CAMHS minimum data set pilots. The CORC website publishes child and practitioner-rated measures, information to support the use of measures and resources to assist implementation of outcome measures.

The costs of developing these systems will need to be considered as part of the wider commissioning processes.

B.3 How to collect data

A carer's perspective

Mental health [services] need to work harder and better with families… support for families will help them with helping their clients more effectively.

Information needs to be collected at every stage of the care pathway and for every contact if clinically appropriate; ensure data completeness at key time points during the care pathway for paired outcome measurement and monitoring of change; it should incorporate the perspectives of both the child or young person and the family or carers where appropriate. In order to gather this information successfully, clinicians need to work in partnership with children and young people and their families and carers in all aspects of the assessment and treatment process. They need to administer a comprehensive range of Patient Reported Outcomes Measures (PROMs), alongside Patient Reported Experience Measures (PREMs) and monitoring of goals.

B.4 What to collect?

It is important that specific outcome measures are selected in partnership with the child or young person to ensure the goals and outcomes that are most important to them are monitored. Services should use PROMS to support this collaboration.

To support the continuous monitoring of outcomes to guide treatment, clinical practice and service developments, routine data collection processes need to be put in place and the principles of CYP IAPT built into the designs of CAMHS and CEDS-CYP. This requires investment in primary data collection systems that support the clinical usefulness of the outcome data in 'real-time' and streamlining the data collection process with the establishment of standardised outcome measures for use across services.

There are broadly 3 types of information that should be collected, reported and used to guide clinical practice and improve service design:

- Information about the severity of eating disorder features, general mental health problems, general functioning and wellbeing, physical health, as well as coexisting mental health problems such as depression and anxiety disorders. This can include long-term follow-up data. (provided by PROMs and clinician-rated outcome measures)
- Information about the attitudes and experiences of the child or young person and family towards the treatments and service being provided (provided by PROMs.
- Care pathway, clinical practice and service development, design and usage information, including clock starts and stops, referral pathways, and specific information about the treatment provided and appointments attended.

When the clock stops, data should be collected to guide treatment as well as collated on a service level and nationwide basis. Such data should be used to help service providers improve care and obtain accreditation via the networks that will be set up in collaboration with the Royal College of Psychiatrists' College Centre for Quality Improvement (CCQI). Accreditation enables services to show that they are leaders in the care and treatment of children and young people with an eating disorder, see Section 6.2, for information on CCQI's accreditation programme.

It is recommended that a minimum set of data items are collected in collaboration with the child or young person, and parent and carer where appropriate. These data should be used to:

- monitor progress towards treatment goals
- guide treatment and supervision
- inform service improvements and delivery.

The measures listed in Table 10 are included in the MHSDS, which also include data items for CAMHS. This table represents an example of the minimum set of measures that should be used for children and young people with an eating disorder, however, other measures should be added as relevant to the child or young person's presentation (for example, measures for obsessive-compulsive disorder or quality of life measures).

Table 10: Outcome measures (all items to be mapped to MHSDS)

When to collect	Child/young person	Parent /carer	Clinician rated
At assessment (a) *what is the problem?* (b) *what do you want to change?/what goals do you want to set?*	**General functioning**	**General functioning**	**General functioning**
	HoNOSCA-YP SDQ	HoNOSCA-Parent SDQ	HoNOSCA CGAS
	Mental health symptom tracker	**N/A**	**N/A**
	EDE-Q Other symptom measures as relevant (for example, RCADS)		
	Physical health symptom tracker	**N/A**	**N/A**
	Percentage median BMI		
	Family functioning	**Family functioning**	**Psychosocial complexity**
	Score 15 – family functioning measure	Score 15 – family functioning measure BPSES	Current view tool
During partnership/therapy (c) *How are we getting on together?* (d) *How are things going?* (e) *Symptom and goal tracker session by session*	**Alliance**	**Alliance**	**N/A**
	SFQ	SFQ	
	Goals	**Goals**	**N/A**
	GBOs ORS (13+) ORS (6-12)	GBOs	
	Mental health symptom tracker	**N/A**	**N/A**

	EDE-Q Other symptom measures as relevant (for example, RCADS)		
	Physical health symptom tracker	**N/A**	**N/A**
	Percentage median BMI		
At review and last session *(f) Have we done as much as we can review T1 scores with last scores* *(g) It is a shared decision to close or refer on* *(h) How has this experience been generally*	**General functioning**	**General functioning**	**General functioning**
	HoNOSCA-YP SDQ	HoNOSCA SDQ	HoNOSCA CGAS
	Mental Health symptom tracker	**N/A**	**N/A**
	EDE-Q Other symptom measures as relevant (for example, RCADS)		
	Physical Health symptom tracker	**N/A**	**N/A**
	Percentage median BMI		
	Family functioning	**Family functioning**	**N/A**
	Score 15- family functioning measure	Score 15 – family functioning measure BPSES	
	Goals	**Goals**	**N/A**
	GBOs ORS (13+) ORS (6-12)	GBOs	
	Experience of care	**Experience of care**	**N/A**
	CHI ESQ-YP	CHI ESQ-Parent	

Key: BPSES = Brief Parental Self-Efficacy Scale; BMI = body mass index; CGAS = Children's Global Assessment Scale; CHI-ESQ = Commission for Health Improvement Experience of Service Questionnaire; EDE-Q =Eating Disorder Examination Questionnaire; GBOs = Goals Based Outcomes; HoNOSCA = Health of the Nation Outcome Scales; MHSDS = Mental Health Services Data Set; ORS = Outcomes Rating Scale; RCADS = Revised Child Anxiety and Depression Scale; SDQ = Strengths and Difficulties Questionnaire; YP = young person

Minimum outcome measurement data has to be collected to establish treatment goals, check symptom improvement and experience of care. The site has links to the measures in Table 10, including service user, family and practitioner-rated measures.

Appendix C: Information Sharing and Capacity

C.1 Information sharing and parental involvement

Where children have the capacity to make a decision, they should be encouraged to involve their parents (or others with parental responsibility). However, when children with capacity

- insist that their parents should not be involved in, or even have knowledge of, proposed treatment or care, and
- their well-being is dependent on that care, and
- it is in their best interests to proceed without parental involvement

practitioners should proceed accordingly (R (Axon) v Secretary of State for Health 2006 EWHC 37).

C.2 Capacity

A young person aged 16 or 17 is assumed to have capacity (Mental Capacity Act HMSO, 2005 Section 1, Principle 1). When a young person lacks capacity because of an impairment of, or a disturbance in the functioning of, the mind or brain, the Mental Capacity Act applies in the same way as it does to adults. However if a young person is unable to make a decision for another reason, for example, because he or she is overwhelmed by its implications, the common law principles set out in Gillick will apply (HMG, 2005).

The absence of consent can be overridden in the public interest when a child or young person is, or may be, at risk of significant harm. That harm need not be the result of abuse or neglect but can simply be the ‘impairment of health or development’ (Children Act 1989 HMSO, 2004), (HMG;, 2015). The measures taken to eliminate or reduce the risk must be lawful and proportionate.

Information sharing agreements should be in place to support sharing, but the absence of an agreement should never obstruct sharing. The above principles apply to information sharing but they also apply generally to the provision of treatment and care to children and young people with eating disorders.

Appendix D: Physical Risk Assessment Information

D.1 SNOMED Measures

The following measures combine those used for adults and children and young people. Practitioners should be aware of this and only use age-appropriate measures. These measures are yet to be published and the HSCIC website should be checked for the final version.

Table 11: SNOMED measures and their respective codes

Domain	SNOMED Concept	SNOMED CODE
Psychological		
1	Family therapy (regime/therapy)	51484002
2	Cognitive - behaviour therapy (regime/therapy)	304891004
3	Guided self-help cognitive behavioural therapy (regime/therapy)	444175001
4	Interpersonal psychotherapy (regime/therapy)	443730003
5	Focal psychodynamic therapy (regime/therapy)	984421000000104
6	Informing patient (procedure)	310866003
Physical		
7	Weighing patient (procedure)	39857003
	Body weight (observable entity)	27113001
	Weight loss (amount) (observable entity)	363806002
8	Measuring height of patient (procedure)	14456009
	Body height measure (observable entity)	50373000
	Growth velocity centile (observable entity)	248340003
9	Measurement of body mass index (procedure)	698094009
	Body mass index (observable entity)	60621009
	Body mass index centile (observable entity)	446974000
	Child body mass index centile (observable entity)	896691000000102
	Percentage median body mass index for age and sex (observable entity)	990291000000106
10	Pulse taking (procedure)	65653002
	Pulse rate (observable entity)	78564009
11	Blood pressure taking (procedure),	46973005
	Blood pressure (observable entity)	75367002
	Systolic blood pressure (observable entity)	271649006
	Diastolic blood pressure (observable entity)	271650006
	Postural drop in blood pressure (finding)	271648003
12	Temperature taking (procedure)	56342008
	Body temperature (observable entity)	386725007
13	Neurovascular assessment of lower limb (procedure)	424653005
14	Neurovascular assessment of upper limb (procedure)	424342008

15	Standard electrocardiogram (procedure)	164847006
16	Sit up, squat, stand test (procedure)	990281000000109
17	Skin assessment (procedure)	225397006
	Purpuric rash (disorder)	284078000
Smoking status		
18	Smoking assessment (procedure)	196771000000101
	Tobacco use and exposure (observable entity)	229819007
	Tobacco smoking consumption (observable entity)	266918002
19	Smoker (finding)	77176002
20	Ex-smoker (finding)	8517006
21	Current non smoker but past smoking history unknown (finding)	405746006
22	Never smoked tobacco (finding)	266919005
Lifestyle		
23	Assessment of lifestyle (procedure)	443781008
24	Exercise status screening (procedure)	171253004
25	Dietary intake assessment (procedure)	225388007
26	Substance misuse assessment (procedure)	777041000000105
27	Alcohol consumption screening (procedure)	171208001
Laboratory measurements		
28	Hemoglobin A1c measurement (procedure)	43396009
29	Fasting blood glucose measurement (procedure)	271062006
30	Glucose measurement, urine (procedure)	30994003
31	Complete blood count (procedure)	26604007
32	Urea and electrolytes (procedure)	252167001
33	Phosphate measurement (procedure)	104866001
34	Albumin measurement (procedure)	26758005
35	Creatinine measurement (procedure)	70901006
36	Protein kinase measurement (procedure)	104903006
37	Fasting blood lipids (procedure)	270927009

D.2 Physical Risk Guidance

Table 12 contains details of investigations and the guidance on how to evaluate the level of physical risk to which the patient is exposed

Table 12: Physical Risk Guidance from the Eating Disorder NICE guideline (2004)

System	Examination	Moderate risk	High risk
Nutrition	BMI[a]	<15	<13
	BMI centiles	<3	<2
	Weight loss/week	>0.5kg	>1.0kg
	Purpuric rash		+
Circulation	Systolic BP	<90mm Hg	<80mm Hg
	Diastolic BP	<60mm Hg	<50mm Hg
	Postural drop	>10mm Hg	>20mm Hg
	Pulse rate	<50 bpm	<40 bpm
	Extremities		Dark blue/cold
Musculo – skeletal + (Squat Test*)	Unable to get up without using arms for balance	+	
	Unable to get up without using arms as leverage		+
	Unable to sit up without using arms as leverage	+	
	Unable to sit up at all		+
Temperature		<35ºC	<34.5ºC
Investigations	FBC, urea, electrolytes (including PO4), LFT, albumin, creatinine kinase, glucose	Concern if outside normal limits	K<2.5 Na < 130 Po4 <0.5
	ECG	Rate < 50	Rate < 40 Prolonged QT interval

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[a] When assessing or treating children and young people, BMI centiles and not absolute BMI should be used.

Appendix E: System Dynamic Service Modelling Tool

NHS England appointed Central Southern Commissioning Support Unit, working with Oxford Health and Healthcare Decisions, in October 2014 to develop a modelling tool for CAMHS. This tool will support commissioners, wider health, and social care communities to review current CAMHS (including eating disorder services) and plan future investment in CAMHS (Tier 2-4) across the whole health, social care and education pathway. A beta version of the modelling tool and the supporting 'business guide' is available via the CSU website.

Appendix F: Therapeutic Engagement Questions

SUMMARY OF KEY QUESTIONS THE MEASURES SEEK TO ANSWER AT DIFFERENT STAGES OF THERAPEUTIC ENGAGEMENT

"What's the problem?" (assessment) This is understanding the issue the young person or family have come for help with

"What do you want to change?" (goals or aims of therapy) – this is understanding the **specific** goals the young person or family have - the things they want to work on in coming to a service

"How are we getting on together?" (engagement or alliance) It is important to get things right from the start

- **"How are things going?" (Symptom/goal tracking) – this is tracking** to see if things are progressing during an intervention

- **"Have we done as much as we can/need to?"** (collaborative decision to close or refer on) – re-review of question 1 e.g. Time2 SDQ (if not used as tracker in long-term case)
- **"How has this experience been generally?"** (experience of service overall).

Appendix G: Workforce Calculator

NHS England appointed the NCCMH to create a workforce calculator to assist commissioners and providers to work together to establish the correct mix of skills and staff required to meet the Standard.

The Community Eating Disorder Service Workforce Calculator can be downloaded from the NHS England website and will also be available from the NCCMH and University College London websites.

Appendix H: Costing data

The data provided in this section covers unit costs of health and social care (Curtis, 2014). Full details can be found at the PSSRU website.

H.1 Assumptions and sources

Salary/Wages

Salaries are based the mean full-‐time equivalent basic salary for Agenda for Change for the band and role to which they are ascribed. NHS salary estimates have been the sole source of information, unless otherwise stated. (Health & Social Care Information Centre, 2014b),

Working Time

- All data on working days and sickness absence are as reported in Health & Social Care Information Centre (HSCIC Workforce and Facilities Team, 2014)
- Contracted hours are taken from the pay and benefits section on the NHS Careers /Working in the NHS site. The data used here is from 2014.
- Where salary costs are listed, they include employer's national insurance plus 14 per cent of salary for employer's contribution to superannuation.

Qualifications

Qualification costs have been calculated using the method described in "Development of a ready reckoner for staff costs in the NHS" (Netten et al., 1998) and cost information provided by the Department of Health and Health Education England to the Department of Health (Health Education England, 2014).

Travel

In some cases, it will be appropriate to reimburse employees for travel (for example a community psychiatric nurse who works with the home treatment team).

Although there is no information available on average mileage per visit, from July 2014, NHS reimbursement has been based on a single rate for the first 3,500 miles travelled by car (56p) and a reduced rate thereafter, irrespective of the type of car or fuel used (20p). Mileage allowances can be found on the NHS website. The rates are reviewed biannually (May and November).

Overheads

- Information on overheads comes from the summarised accounts of the NHS (NHS Commissioning Board, 2013)
- Management and other non-‐care staff costs were 19.31 per cent of direct care salary costs and included administration and estates staff.
- Non-‐staff costs were 41.97 per cent of direct care salary costs. They include costs to the provider for office, travel/transport and telephone, education and training, supplies and services (clinical and general), as well as utilities such as water, gas and electricity.

Capital Overheads.

- These are based on the new-‐build and land requirements of an NHS office and shared facilities.

- Building cost information has been provided by the National Office of Statistics (Office of National Statistics, 2014) and land cost information has been supplied by the Valuation Office Agency in 2013 to the PSSRU.
- Capital costs have been annuitized over 60 years at a discount rate of 3.5 per cent. Based on the assumption that each team has one shared office.

Multipliers

- London and non-London multipliers are shown in Table 13. These allow for higher and lower costs associated with working in London or nationally. Multipliers are created using the Market Forces Factor (Monitor, 2013), the survey of tender prices (Building Cost Information Service, 2014), and land value information (Curtis, 2014)

Table 13: London Mulitplier data

London Multiplier	1.19 x wages and oncosts 1.39 x capital overheads
Non-London Multiplier	0.96 x capital overheads

H.2 Staff costs and overheads from PSSRU data

H.2.1 Targeted CAMHS Team

Costs can be calculated on a team basis and Table 14 fives a breakdown of the costs of a Targeted CAMHS team.

Table 14: Breakdown of costs for a Targeted CAMHS team

Costs and unit estimation	**2013/2014 value**	**Notes**
Salary plus oncosts	£40,989 per year	Average salary for a team based on national CAMHS data (Devanney et al., 2012)
Overheads		
Management, administration and estates staff	£7,915 per year	
Non---staff	£17,203 per year	
Capital overheads	£3,687 per year	
Working time	42 weeks per year 37.9 hours per week	Unit costs are based on 1,575 hours per year: 210 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
Ratio of direct to indirect time on:		Staff activity was reported at the team level as follows 49% clinical 23% administration and management 13% consultation and liaison 9% education and training 5% research and evaluation (Department of Health, 2002)
Patient---related work	1:0.63	
Face---to---face contact	1:1.06	
Duration of episode		22 per cent of cases lasted for 4 weeks or less, 24 per cent for 13 weeks or less, 18 per cent for 26 weeks or less, 16 per cent for 52 weeks or less and 20 per cent for more than 52 weeks.
Caseload	47 cases per team	Based on 335 teams and 15,653 cases (Devanney et al., 2012).
Unit costs available 2013/2014		
£44 per hour per team member *£72 cost per hour per team member for patient-related activities* *£91 cost per hour per team member for face-to-face contact* *£6,236 average cost per case*		

H.2.2 Clinical staff

Table 15: Consultant Psychiatrists

Costs	Unit cost (2013/14)	Notes
Salary plus oncosts	£112,904 per annum	The mean basic salary for psychiatric consultants (Health & Social Care Information Centre, 2014a) 33.5% can be added to reflect payments for activity such as overtime, shift work and geographic allowances
Qualifications	£92,196 per annum	
Overheads **Management, administration and estates staff.** **Non-Staff**	 £21,801 per annum £37,385 per annum	
Capital Overheads	£4,891 per annum	
Working Time (recommended for use in the calculator)	43.3 hours per week 42.4 weeks per year	Unit costs are based on 1,627 hours per year: 217 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
£103 (£142, including qualifications) per contract hour.		

Table 16: Consultant (medical)

Costs	Unit cost (2013/14)	Notes
Salary plus oncosts	£110,201 per annum	The mean basic salary for medical consultants (Health & Social Care Information Centre, 2014a) 33.5% can be added to reflect payments for activity such as overtime, shift work and geographic allowances
Qualifications	£72,197 per annum	
Overheads		
Management, administration and estates staff.	£21,279 per annum	
Non-Staff	£46,251 per annum	
Capital Overheads	£4,891 per annum	
Working Time (recommended for use in the calculator)	43.3 hours per week 42.4 weeks per year	Unit costs are based on 1,836 hours per year: 212 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014) The contract aims to reduce the number of hours that consultants work, including aligning with the Working Time Directive. Funding assumptions are based on consultants working an average 43.4 hour week. A contract is based on 10.83 programmed activities which are 4 hours in length (Workforce Analysis Team, 2006)
£101 (£140 including qualifications) per contract hour.		

Therapists

Data for cognitive behavioural and multi-systemic therapist could be extrapolated to estimate the staff and overhead costs for related fields.

Table 17 and Table 18 provide data for staff and overhead costs in these areas. Supervisory therapists will be on a higher clinical banding than band 7.

Table 17: Multi-Systemic Therapy

Costs	Unit cost (2013/14)	Notes
Salary plus oncosts	£46,656 per annum	This salary for a multi-systemic therapist is based on salary data for a chartered counselling psychologist (Cary et al., 2013)
Overheads **Management, administration and estates staff.** **Non-Staff**	£9,009 per annum £19,581 per annum	
Capital Overheads	£3,687.00	
Working Time (recommended for use in the calculator)	37.5 hours per week 42.4 weeks per year	Unit costs are based on 1,588 hours per year: 212 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
£50 per hour; £119 per therapy session.		

Table 18: Cognitive Behavioural Therapy

Costs	Unit cost (2013/14)	Notes
Salary plus oncosts	£42,866 per annum	Based on band 7, (Goodyer et al., 2008)
Overheads **Management, administration and estates staff.** **Non-Staff**	£9,358 per annum £20,340 per annum	
Capital Overheads	£3,935 per annum	
Working Time (recommended for use in the calculator)	37.5 hours per week 43.4 weeks per year	Unit costs are based on 1,627 hours per year: 217 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
Ration of direct to indirect time on face-to-face contact	1:1	50% of time is spent on face-to-face contact and 50% on all other activities
£93 cost per CBT session.		

Nursing Staff

Table 19: Specialist community nurse

Costs	Unit cost (2013/14)	Notes
Salary	£31,943 per annum	Based on band 6. 12.7% can be added to reflect payments for activity such as overtime, shift work and geographic allowances
Oncosts	£7,818 Per annum	
Qualifications	£10,514 per annum	
Overheads **Management, administration and estates staff.**	£7,677 per annum	
Non-Staff	£16,688 per annum	
Capital Overheads	£3,687 per annum	
Working Time (recommended for use in the calculator)	37.5 hours per week 42 weeks per year	Unit costs are based on 1,575 hours per year: 210 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
Ration of direct to indirect time on : Patient---related care	1:0.49	Assumption: Specialist nurses spend 32% of time on direct care 22% on care planning, assessment and coordination 20% on administration 11% on management 13% on travelling 1% on other duties. (Ball et al., 2014)
£43 (£50) per hour; £64 (£74) per hour of patient-related work (numbers in brackets include qualifications)		

Table 20: Mental Health Nurse

Costs	Unit cost (2013/14)	Notes
Salary	£25,847 per annum	Based on band 5. 12.7% can be added to reflect payments for activity such as overtime, shift work and geographic allowances
Oncosts	£6,123 Per annum	
Qualifications	£10,514 per annum	
Overheads		
Management, administration and estates staff.	£6,173 per annum	
Non-Staff	£13,147 per annum	
Capital Overheads	£3,687 per annum	
Working Time (recommended for use in the calculator)	37.5 hours per week 42 weeks per year	Unit costs are based on 1,575 hours per year: 210 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
£35 (£39) per hour; £66 (£74) per hour of face-to-face contact; £47 (£52) per hour of patient-related work. (numbers in brackets include qualifications)		

Table 21: Dietitian

Costs	Unit cost (2013/14)	Notes
Salary	£23,475 per annum	Based on band 7, Other resources used (Goodyer et al., 2008)
Oncosts	£5,464 per annum	
Qualifications	£5,777	
Overheads		
Management, administration and estates staff.	£5,588 per annum	
Non-Staff	£12,145 per annum	
Capital Overheads	£5,767 per annum	
Working Time (recommended for use in the calculator)	37.5 hours per week 42.4 weeks per year	Unit costs are based on 1,627 hours per year: 217 working days minus sickness absence and training/study days as reported for NHS staff groups (HSCIC Workforce and Facilities Team, 2014)
Ration of direct to indirect time on face-to-face contact	1:1	50% of time is spent on face-to-face contact and 50% on all other activities
£33 (£36 including qualifications) per hour.		

Further information can be obtained from the PSSRU website.

Appendix I: Checklist to help you prepare for the Standard

Table 22 is a checklist for commissioners to use as an aid to they are prepared for transforming their services.

Table 22: Commissioners Checklist

1	**Baseline current service provision**	**YES**	**NO**
1a.	Do you have a current eating disorder service?		
1b.	Do you have any data about current outcomes, service user feedback and service activity?		
1c.	From these data, can you identify gaps in service when comparing service provision with anticipated need?		
2	**Needs assessment**	**YES**	**NO**
2a.	Have you consulted the relevant data published by Public Health England through the former Child and Maternal Health Observatory?		
2b.	Do you have a JSNA?		
2c.	Has the JSNA ensured that the new service satisfies all legal duties with regard to equality, health inequalities and monitoring improvement?		
2d.	Does the JSNA include the CAMHS Needs Assessment?		
2e.	Do you have a separate CAMHS Needs Assessment?		
2f.	Was the CAMHS Needs Assessment completed with local authority, public health and education partners?		
2g.	If not, have you ensured that they have signed up to the CAMHS Needs Assessment?		
2h.	Have you created an eating disorder needs assessment in line with the CAMHS Needs Assessment and the JSNA?		
2i.	Does the eating disorder needs assessment include the views of children, young people and families?		
2j.	Has current service provision data been included in the prediction of future needs?		
2k.	Does the eating disorder needs assessment include prevalence data on eating disorders for the population?		
2l.	Does the eating disorder needs assessment include demographic data, for example data on age, gender and ethnicity?		
2m.	Does the eating disorder needs assessment include population data, for example data on population, population projections, births, deaths and deprivation?		
3	**Service model**	**YES**	**NO**
3a.	Have you decided to commission a single service for your CCG?		
3b.	If no, have you decided to commission a service with other CCGs?		
3c.	Do you need to commission new services?		
3d.	Have you tested the market in terms of potential providers and agreed the most effective procurement process for any new services identified?		
3e.	Have you viewed and taken into account the Model Specification for Child and Adolescent Mental Health Services: Targeted and Specialist levels (Tiers 2/3)?		

3f.		Have you viewed and taken into account New commissioning tools published for transitions from Child and Adolescent Mental Health Services (CAMHS)?		
3g.		Have you reviewed the CAMHS Payment System Project?		
Do you have a service specification that includes:	3h.	The provision of age-appropriate services?		
	3i.	The provision of culturally appropriate services?		
	3j.	Clear self-referral routes?		
	3k.	A communication plan that includes information on how children, young people, families, carers and other professionals can access services?		
	3l.	A plan outlining how families and carers will be supported, including clear guidance to ensure confidentiality is balanced by the need to keep children and young people safe?		
	3m.	Services that have the capacity to support children with common coexisting mental and physical health problems?		
	3n.	A process for managing the high risk of medical complications? (Paediatric services must be part of the proposal.)		
	3o.	A plan for providing day care or intensive home treatment for those that need more intensive input?		
	3p.	How the recommendations in the Junior MARSIPAN report will be embedded in service delivery?		
4		**Liaison plans**	**YES**	**NO**
Do you have a service specification that includes:	4a.	Local acute paediatric teams linked into eating disorder teams for brief admissions for medical stabilisation?		
	4b.	Provision for monitoring underweight children and young people and management of re-feeding to achieve medical stabilisation?		
	4c.	A lead consultant/champion for acute eating disorder care, as advised in the Junior MARSIPAN?		
	4d.	Local arrangements for CEDS-CYP to work with paediatric teams and provide oversight for children and young people with an eating disorder including regular communication?		
	4e.	A process to ensure that care plans will be completed on a multi-agency basis, in collaboration with children and young people and, where appropriate, their families of carers?		
	4f.	A proposal on how different agencies will work with children and young people with an eating disorder and, where appropriate, their families of carers to enable access to education, employment or training?		
5		**Awareness plan**	**YES**	**NO**
5a.		Does Public Health England provide good ‘balanced’ information to children and families about healthy weight and eating disorders?		
5b.		Does the CEDS-CYP have a plan to provide awareness-raising and first-help training to primary care and schools?		
6		**Care pathways and protocols**	**YES**	**NO**
6a.		Is there a plan to provide clear routes to a CEDS-CYP from medical and non-medical professionals?		

6b.	Does the local proposed care pathway meet the Access and Waiting Time Standard?		
6c.	Does this intended service provide a full range of NICE-concordant treatments for example, evidence-based family therapy and CBT for eating disorders?		
7	**Transition plans**	**YES**	**NO**
7a.	Is there a plan for how transitions between services will be kept to a minimum?		
7b.	Is there a plan to ensure clear and efficient transition arrangements to adult services?		
7c.	Is there a plan to ensure clear and efficient transition arrangements across geographical boundaries?		
8	**Recruitment plans**	**YES**	**NO**
8a.	Does your provider have appropriately trained and experienced staff to meet the recommendations in Section 4.3 of this guide?		
8b.	If ‘no’, do they have a recruitment plan?		
9	**Training plan**	**YES**	**NO**
9a.	Is your provider part of CYP IAPT or do they plan to adopt CYP IAPT principles in the near future?		
9b.	Is there a plan for continued training and supervision of staff in the provision of evidence-based NICE-concordant treatment?		
9c.	Is your Local Education and Training Board aware of the number of professionals your provider has identified who need training and is there a regional plan to meet the need?		
9d.	Is there a comprehensive training programme for non-clinicians that includes awareness raising in primary care and early support?		
9e.	Is there a comprehensive training programme for all staff to improve the management and service delivery for all those involved in the provision of service?		
10	**Outcome measurement plan**	**YES**	**NO**
10a	Do you have an outcome measurement protocol?		
10b	Are you monitoring the number of cases that are meeting the standard?		
10c	Does your provider have an appropriate electronic records system?		
10d	If not, do they have plans to provide the data and how will they do this in the longer term?		
10e	Is the provider part of a quality improvement or accreditation network?		
10f.	If not, how will the provider report on outcomes and benchmark their performance with other areas?		
11	**Benefits realisation plan**	**YES**	**NO**
11a	Do you have a benefits realisation plan that the provider has signed up to?		

Appendix J: Helpful resources

A number of standards and guidelines exist that may be helpful to providers and commissioners regarding information about core components of high-quality eating disorder services. There are also a number of materials to support families and carers of children and young people. A few of these have been mentioned in this appendix.

J.1 Standards, guidelines and online resources

- Australian and New Zealand Eating Disorder Guidelines (2014) are updated guidance based on evidence that has emerged since the 2004 NICE guideline
- Beat Assured Standards are quality standards based on experience of those affected by eating disorders.
- Children and Young people's Empowerment Project (CHILYPEP) is a charity works alongside children and young people aged 8 to 25, to find ways of involving them in the decisions that affect their lives. They provide information on how to involve children and young people in the commissioning process.
- Junior MARSIPAN (Management of Really Sick Patients under 18 with Anorexia Nervosa) provides guidance and recommendations on service requirements for assessment and treatment of children and young people with anorexia nervosa.
- Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers (2015)
- MindEd is a free e-learning portal that aims to help adults identify and understand children and young people's mental health issues. The target audience are adults working in universal, targeted and specialist settings including CAMHS. For example, there is an e-learning session that describes eating problems within the general population, and explains how to recognise anorexia nervosa, bulimia and binge eating disorders. The session concludes with illustrating how to screen for eating disorders in primary care and discussing the possible interventions that can be applied.
- Quality Network for Eating Disorders (QED) provides useful information about core and specific standards for a quality assurance framework.
- Thrive model is a proposed model for CAMHS that presents an alternative way of conceptualising and potentially delivering services.
- Worldwide Charter for Action on Eating Disorders is a charter of basic rights for those affected by eating disorders with an outline of eating disorder service quality markers produced by the Academy for Eating Disorders in collaboration with professional and service user/carer organisations around the world.
- Working together to safeguard children (March 2015)

J.2 Educational material for families and friends

Bryant-Waugh R, Lask B. Eating Disorders: A Parents' Guide. Hove: Routledge; 2013.

Treasure J, Alexander J. Anorexia nervosa: A Recovery Guide for Sufferers, Families and Friends. Hove: Routledge; 2013.

Treasure J, Smith G, Crane A. Skills-based Learning for Caring for a Loved One with an Eating Disorder: The New Maudsley Method. Hove: Routledge; 2007.

Appendix K: Expert Reference Group members

Table 23 lists the members of the Expert Reference Group and their specialist areas.

Table 23: Expert Reference Group Members

Name	Title	Specialist Area
Professor Peter Fonagy (Chair)	Freud Memorial Professor of Psychoanalysis and Head of Research Department of Clinical, Educational and Health Psychology, University College London	Clinical psychology; psychoanalysis
Professor Tim Kendall (Facilitator)	Director of National Collaborating Centre for Mental Health (NCCMH) and Consultant Psychiatrist	Psychiatry, evidence-based guidance development
Mr Andrew Roberts	National Service and Commissioning Advisor, NCCMH	Health commissioning, service management
Dr Rachel Bryant-Waugh	Consultant Psychologist and Joint Head, Feeding and Eating Disorders Service, Great Ormond Street Hospital. Lead Psychologist, Department of Child and Adolescent Mental Health. National Clinical Advisor, NCCMH	Clinical psychology
Professor Anthony Bateman	Consultant Psychiatrist and Psychotherapist, Honorary Senior Lecturer and Visiting Professor at University College London	Psychiatry and psychoanalysis
Ms Lauren Becker	Research Assistant, NCCMH	Technical Team
Professor Sarah Byford	Professor of Health Economics	Economic evaluation of mental health and social care services, including services for children and adolescents
Ms Janet Eastham	Service user representative	Service user/carer advice
Professor Ivan Eisler	Emeritus Professor of Family Psychology and Family Therapy, Kings College London	Psychology
Ms Gladys Ellis	Senior Systemic Family Psychotherapist and Team Coordinator, South London and Maudsley Child and Adolescent Eating Disorders Service	Family psychotherapy
Professor Christopher Fairburn	Wellcome Principal Research Fellow and Professor of Psychiatry, Department of Psychiatry, Oxford University	Psychiatry
Ms Harriet Clark	Programme Manager, College Centre for Quality Improvement (CCQI), Royal College of Psychiatrists.	Technical Team: Access and Waiting Times network development
Dr Lee Hudson	Consultant Paediatrician, Great Ormond Street Hospital	Paediatrics
Ms Joanna Levy	Deputy Head of Counselling, King’s College London	Psychology; student counselling

Ms Jacqueline Mann	Carer Representative and Nurse Consultant	Service user/carer advice
Mr Tim McDougall	Nurse Consultant, Clinical Director (Tier 4 CAMHS) and Lead Nurse (CAMHS), Cheshire and Wirral Partnership NHS Foundation Trust	Nursing; CAMHS
Dr Margaret Murphy	Consultant Child and Adolescent Psychiatrist and Clinical Chair, Secure and Specialised Mental Health Programme of Care, NHS England.	Child and adolescent psychiatrist
Dr Dasha Nicholls	Consultant Child and Adolescent Psychiatrist, Joint Head, Feeding and Eating Disorders Service, Great Ormond Street Hospital.	Child and adolescent psychiatrist
Ms Anne O'Herlihy	Child and Adolescent Mental Health Project Manager NHS England	NHS England Clinical Policy and Mental Health Strategy
Ms Kathryn Pugh	Child and Adolescent Mental Health Programme Manager, NHS England Medical Directorate	NHS England Clinical Policy and Mental Health Strategy
Mr Neil Ralph	Clinical Psychologist, Health Education England	Psychology
Dr Sandeep Ranote	Psychiatrist and Clinical Lead of CAMHS Strategic Clinical Networks	Child and adolescent psychiatry
Ms Susan Ringwood	Former Chief Executive, Beat	Service user/carer advice
Ms Saira Shamim	Project Manager, NCCMH	Technical Team
Dr Anne Stewart	Consultant Child and Adolescent Psychiatrist, Oxford Health	Child and adolescent psychiatry
Ms Amanda Tuffrey	Service User Representative	Service user and carer advice
Dr Deborah Waller	General Practitioner, Beaumont Street Surgery, Oxford	General practice
Professor Glenn Waller	Professor of Clinical Psychology, University of Sheffield	Psychology; CBT

Appendix L: The Roles of the CEDS-CYP MDT

Assessment

Assessment of an eating disorder is somewhat different from the assessment of other mental health problems. It needs to cover both physical and psychological domains and also include a family assessment. There should be a focus on the child or young person’s current functioning as well as interruptions to development across multiple domains (medical, psychological, social, educational). The support needs of all family members should be evaluated. It is recommended that the assessment is carried out by a minimum of two members of the multidisciplinary team to ensure that the required professional expertise is brought to the process.

Medical and nursing staff will need to take responsibility for ensuring the child or young person’s physical state is comprehensively assessed and appropriate medical management plans put in place. Children and young people with coexisting medical conditions may be at particularly high medical risk and require careful evaluation of the impact of the eating disorder on the coexisting condition. Children and young people at particularly high risk include those with type 1 diabetes, those who are engaging in self-induced vomiting in the context of taking regular oral medication to manage a coexisting condition, and those who may be pregnant. See Table 24 for common indications that either admission or increased intensity of treatment may be appropriate.

Professionals with child and adolescent mental health training (for example, psychologists, psychiatrists and mental health nurses) will need to ensure that mental state and psychosocial aspects of the child or young person’s presentation are comprehensively assessed and appropriate management and support plans put in place. Assessing staff should have the knowledge and expertise to be able to distinguish between an eating disorder and other conditions characterised by the common features of eating disorders, including reduced food intake, low weight, vomiting and feelings of fullness. Assessment of cognitive function by a psychologist may be required to ensure that treatment is provided in a manner commensurate with the child or young person’s level of understanding.

Treatment

Treatment for an eating disorder needs simultaneously to address a number of areas of development and functioning. Similar to assessment, multidisciplinary input is required to ensure that the treatment is integrated, person-centred, reflects the principles of participation and joined decision making and remains outcome and goals focus within which all relevant problem areas are comprehensively managed. These might include the following:

- monitoring and management of the child or young person’s physical/medical state and functioning overseen by medical staff (a paediatrician or GP with specific expertise in eating disorders) or appropriately trained nursing staff
- monitoring and management of the child or young person’s general mental state, overseen by a psychologist or psychiatrist
- nutritional rehabilitation overseen by a dietician
- individual psychological interventions provided by psychologists, nurse therapists or other appropriately trained and qualified therapists

- family interventions (to include multi-family group interventions), provided by family therapists, psychologists, nurse therapists or other appropriate trained and qualified therapists
- group interventions and other psychosocial interventions, provided by psychologists, nurses or occupational therapists
- home treatment and mealtime support, provided by nursing and support staff
- management of psychotropic medication where prescribed, including for any coexisting mental health problems (for example, depression and anxiety), overseen by a psychiatrist.

Follow-up

At the end of treatment and at follow-up, multidisciplinary input is also required to cover the full range of domains of functioning. Typically this will require medical or appropriately trained nursing staff to assess medical state and physical development and any residual risk as well as a mental health professional (such as a psychiatrist, psychologist or mental health nurse) to assess psychological state and functioning and any residual risk.

Table 24: Common indications for admission/increased intensity of treatment from assessment

Physical	Severe weight loss (either rapid or extremely low weight) Electrolyte disturbance Dehydration Hypothermia Significant renal function abnormalities Cardiovascular complications (for example, hypotension, tachycardia, bradycardia) Intractable vomiting
Psychological	Severe depression Suicidal ideation or intent Other significant psychiatric disturbance
Other	Families or carers unable to manage required level of supervision and input Failed community treatment