



# Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care

# Guidance for commissioners and providers

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Publishing approval number: 000957

Version number: 1

First published: August 2019

Prepared by: NHS England with NICE and the National Collaborating Centre for Mental Health

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- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

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# **Key Statements**

These statements were developed by people with experience of receiving treatment for an eating disorder, as well as their family members and carers. They reflect what people want and need from eating disorder services.

#### People with experience of an eating disorder

I will receive collaborative, personcentered treatment that is focused on my needs and not just my weight or BMI (body mass index), to help me recover mentally as well as physically. I want professionals to show compassion, understanding and trust, while not making assumptions based on my diagnosis. Professionals who are working with me will understand how eating disorders can affect people differently, and how they might get in the way of people accepting help.

I want people involved in my care to communicate with me and be open and transparent, explaining why certain decisions are made. I want to be able to voice my opinion and to be fully informed throughout my treatment.

I want everybody involved in my care to communicate with each other. If I need inpatient treatment, then I want my inpatient and community team to work with each other. I want to stay connected to the 'real world' so I don't feel like I have to start afresh after being discharged. I need the right support to help me transition back to the community.

My treatment will always be based on the possibility of recovery and on helping me re- establish who I am, regardless of my past or the length of my illness. People won't give up on me. I will be involved in creating my care plan, which will include information about any transitions I have to make (geographical, age-based or inpatient to community), what to do if I am in crisis, how I can stay well and what to do if I experience a relapse.

I have the right to **nominate a person to support me** and my wishes will be respected around who I would like to be involved in my care or not.

I want my community team to be trained and competent to offer evidence-based treatment, as well as a range of other support activities and groups.

I would like my community team to be made up of a range of professions and I would like to meet all the individuals involved in my care. I should know who my care coordinator is and who to contact if I find myself in distress.

I will be supported to **make positive choices**, but I will also be supported when I struggle to make these decisions for myself or I experience any setbacks.

I would like the inpatient unit to offer a **structured treatment plan** with regular groups and activities I can choose to attend no matter what weight I am, alongside individual therapy.

If I experience a relapse, I will be able to self-refer to the nearest eating disorder service and I will be seen as quickly as possible. I will not have to go back on to a waiting list or feel like I have to become worse to be seen.

#### Families and carers

As families, carers, partners, friends or support people, we will be able to access and receive support to help our loved ones with an eating disorder, regardless of whether they are getting treatment or not. Services will understand that carers who are partners and carers who are parents may have different needs and will give them the right level of information and support.

Services will understand the distress we can experience and will help us to get support for our own mental and physical health.

#### 1. Introduction

#### 1.1 Background

Following a significant expansion of services for children and young people with eating disorders, over recent years, there is now increasing commitment across a range of stakeholders to improve both timely access to, and the quality of evidence-based treatment in, eating disorder services for adults and older adults. The Parliamentary and Health Service Ombudsman (PHSO) recently published, 'Ignoring the Alarms: How NHS Eating Disorder Services are Failing Patients'. This establishes a clear rationale for localities to focus on improving care for adults with eating disorders.<sup>1</sup>

As part of the NHS Long Term Plan, local areas will be supported to redesign and reorganise community mental health services to move towards a new place-based, multidisciplinary service across health and social care aligned with primary care networks. By 23/24 there will be new and integrated models of primary and community mental health care to support at least 370,000 adults and older adults per year including those living with eating disorders, to give them greater choice and control over their care and support them to live well in their communities.

Alongside this work, the New Care Models programme will give NHS led provider collaboratives the opportunity to redesign the pathway for adults with Eating Disorders to bring care closer to home by giving them the responsibility for managing the budget associated with specialist care for this group.

Therefore, through a rebalancing of provision, from a focus on inpatient services to expansion of community based services, adults with eating disorders will be able to access treatment earlier, and closer to home, leading to better outcomes for them and their families.<sup>2</sup>

# 1.2 Purpose and scope of this guidance

This guidance is primarily for commissioners and providers of adult eating disorder services (age 18 years and above), as well as people who use services and those who support them. It focuses on the optimum model of delivery (see Section 2), including information about the required skill mix in dedicated community eating disorder teams to improve access to treatment, care and support. It covers care provided in the community, as well as inpatient or intensive day patient treatment where required.

The guidance covers services for a range of eating disorders; anorexia nervosa, bulimia nervosa, binge eating disorder and other specified feeding and eating disorders (OSFED).

This guidance should be read alongside a number of other guides, including:

- Access and Waiting Time Standard for Children and Young People with an Eating Disorder:
   Commissioning Guide,<sup>4</sup> particularly in relation to managing transitions between services
- Eating Disorders: Recognition and Treatment NICE Guideline (NG69)
- Eating Disorders Quality Standard (QS175)<sup>4</sup>
- MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa

- <u>Guidance for Commissioners of Eating Disorder services</u> from the Joint Commissioning Panel for Mental Health<sup>6</sup>
- Addendum to the Children and Young People's Commissioning Guide to include Inpatient and Intensive Day Care episodes of care
- A Framework for Community Mental Health Support, Care and Treatment for Adults and Older Adults (forthcoming).

#### 1.3 Co-production

Co-production is key to developing and improving eating disorder services. To genuinely coproduce services, commissioners should develop and implement local plans in collaboration with: people with experience, service providers and partner agencies. More information can be found here.

# 2. Optimal model of service delivery

Clinical consensus indicates that the optimal model of service delivery for people with an eating disorder is a dedicated, multidisciplinary eating disorder service. Care should be delivered in the community, supported by intensive day patient or inpatient treatment for people with a high level of physical or psychiatric risk that cannot be managed safely in the community (see Section 3.9). Adult Eating disorder services should provide a seamless pathway for young adults supporting a positive experience of transitioning from children and young people (CYP)-CED services where needed and avoiding unhelpful 'cliff edges in care'.

A comprehensive community eating disorder (CED) service should ideally serve a wider geographical area (recommended 1 million or greater all-age population),<sup>7</sup> with the skills and competences (see Appendix I in the helpful guide) to provide care to a range of people, including:

- people presenting for the first time
- people with long-term and enduring problems
- those with comorbid conditions (physical and mental health as well as drug and alcohol use),
   and
- young people transitioning from children and young people (CYP)-CED services.

# 2.1 Key functions of care

The core aim of a comprehensive CED service is to deliver timely, effective, evidence-based treatment that meets the needs of a person with an eating disorder. A CED service should:

- provide evidence-based treatment, care and support for the full range of eating disorder diagnoses, including binge eating disorder and OSFED
- accept all presentations from people who present for the first time to those with long-term problems, regardless of weight or BMI (body mass index)
- collaboratively use **routine outcome measurement** to support a person to identify and meet their goals for recovery (see Appendix E)
- have the skills to provide care across the lifespan, from younger people to older adults
- provide medical monitoring (see Section 3.6)
- offer intensive community treatment, or be able to support day patient treatment, to reduce unnecessary or inappropriate inpatient admissions

- be **proactive** in engaging people in treatment as soon as possible, as well as those who are returning to active treatment following a period of recovery
- **support and empower** families, partners, carers and the person's support network
- offer advice, support and consultation to other services involved in a person's care
- provide coordinated care (see Section 2.4) work with other services to reduce and prevent gaps in care during service transitions (age-related, geographical or community to inpatient transitions); using clear protocols and joint working agreements
- respond appropriately to issues relevant to competence, capacity, consent, safeguarding and information-sharing
- have clear processes around managing risk and safety as well as unattended appointments (including clear follow-up protocols to engage a person and prevent inappropriate discharge)
- provide **appropriate clinical supervision** to ensure professionals remain competent to deliver evidence-based treatment (see Appendices and Helpful Resources Appendix I, Section 3)
- **improve awareness** of the service in the community, the importance of early identification and reduce the stigma around eating disorders to increase help-seeking in the local population.

#### 2.2 Delivery of care

<u>Table 1</u> outlines the ideal staffing mix of a comprehensive, multidisciplinary and skilled CED service covering a range of functions, based on clinical consensus. A member of the CED service should be allocated as the person's main contact or care coordinator, with ongoing input from other professionals as needed. Further information on workforce is in Appendix I of Helpful Resources.

Table 1: Ideal staffing mix of a comprehensive CED service		
Profession	Responsibilities	
Administrative staff	Provide administrative support to the service	
Dietician	Provide dietetic assessment, advice and treatment to patients and to staff; support staff to devise meal plans, manage risk related to refeeding; oversee the nutritional care plan and psychoeducation regarding nutrition, weight and food	
Family therapist	Provide family therapy and support other clinicians within the team to work with people's families, partners, carers and support network	
Medical professionals (e.g. clinical nurse consultant, GP, physician)	Medical monitoring, blood tests, electrocardiograms (ECGs); liaise with other medical professionals (e.g. gastroenterologists and primary care; see Section 3.8, 3.6)	
Nursing staff	Initial patient contact, facilitate engagement, assessments, deliver evidence-based individual and family psychological interventions, liaise with wider network	
Occupational therapists	Support and develop people's lives outside of an eating disorder (e.g. meal preparation, life skills training, social skills training, sensory processing) and provide anxiety, assertiveness and anger	

	interventions
Peer support workers (see Appendix G)	Support the recovery model, act as a mentor, assist in the delivery of peer support groups as well as eating disorder training, education and awareness (with appropriate training and clinical supervision)
Psychiatrists	Provide biopsychosocial assessment, medical and psychological treatments and coordination of care, including assessment, diagnosis and management of comorbidities, and monitoring and managing of physical and psychological risks, especially for people with complex needs. Psychiatrists also have medico-legal responsibilities around using the Mental Health Act <sup>8</sup> and Mental Capacity Act, <sup>9</sup> if needed
Psychologists	Assessment, formulation and delivering evidence-based psychological interventions for eating disorders and co-existing mental health problems
Social workers	Provide individual, couple and family support; facilitate support groups and link to other community resources
Support workers (including assistant psychologists)	Provide interventions and support for individuals or groups (with appropriate supervision and training); work with clinicians to collect and analyse outcomes and feedback

The CED service may operate through one central location or through a hub and spoke model, across neighboring areas that function as one comprehensive CED service, depending on local population needs. <u>Figure 1</u> outlines the components of a comprehensive CED service and how this may be delivered.

# 2.3 Assessing the needs of the local population and developing an adult eating disorder service

An effective CED service requires commissioners and providers to have a firm understanding of local demand, considering the whole range of needs, beyond just direct medical or psychological treatment. This should not simply be based on current or historical referral rates, but should be based on prevalence data, the completion of an equality and health inequalities assessment as well as engagement with local VCSE and other non-statutory organisations who provide services for people with an eating disorder, to gain further information regarding local need and demand.

- Current data indicates a 6% point prevalence rate for the full range of eating disorders, in both genders across the adult years. <u>The Public Health Fingertips</u> tool provides local prevalence estimates to assist in the planning and commissioning of services.
- Commissioners should also note that increasing awareness of available services and the removal of barriers to accessing care can lead to an increase in demand for services, which may then require adjustments to local prevalence estimates.

Based on the assessment of local need and demand, commissioners and providers should determine current eating disorder service provision, identify any gaps, and create a plan to improve delivery of services. Commissioners should consider:

- the size of population to be served (recommended 1 million or greater all-age population)
- the general level of coexisting mental health and physical health problems and how these will

be or are currently managed, including joint delivery of care across services

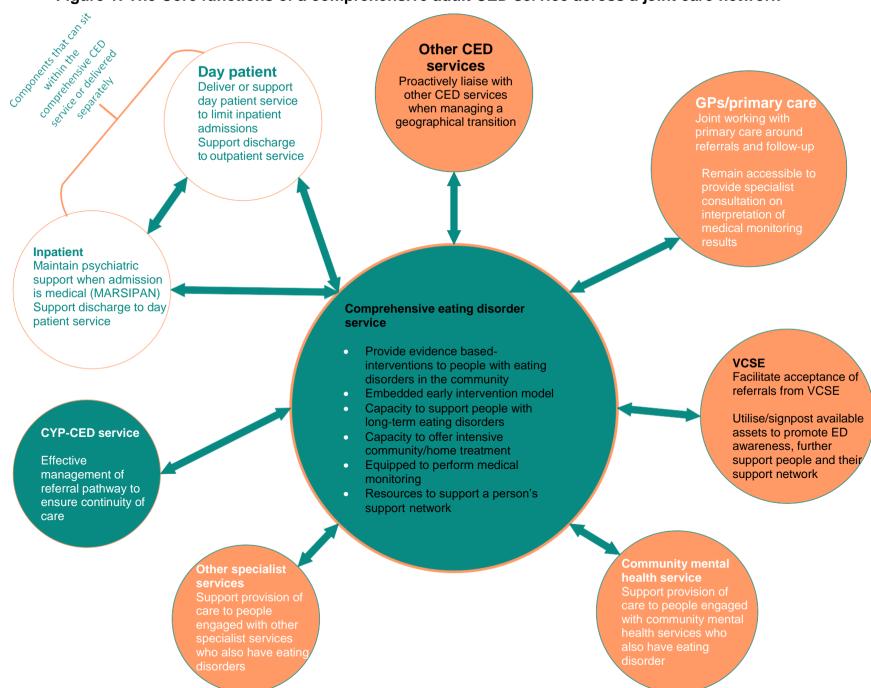
- the capacity and effectiveness of current services to deliver both early intervention and longterm care
- the anticipated impact of new or proposed services in meeting the need
- developing a local model of care delivery, including care pathways, based on local needs and resources (including the local availability of inpatient or intensive day patient options)
- clarifying (within the service and the CCG) the responsibilities for commissioners and providers, especially in terms of links with inpatient units and funding for beds
- overall workforce requirements, including location of multidisciplinary teams (whether they will be co-located or can form a virtual team with regular meetings) and differential skillsets required for particular presentations
- education and training for other clinicians and professionals across health care, social care and education sectors
- improving general awareness and understanding in the wider community of eating disorders and common associated comorbidities.

To create a viable CED service that can cover a wider geographical area, commissioners and providers will need to work together and decide whether to a service is to cover a single CCG or cover a cluster of CCGs or across an STP or MHS led provider collaborative footprint. NHS England has <u>published resources</u> for commissioners to guide the implementation of mental health services within a wider joint strategy.

Challenges and solutions which may arise when establishing and developing a CED service are outlined in Appendix D, alongside potential solutions that can be put into practice.

**Figure 1** on page 11 summarises the core functions of the adult CED service incorporating inpatient and day care, and joint working with other community services and GP and primary care services to ensure appropriate referrals and follow-up.

Figure 1: The Core functions of a comprehensive adult CED service across a joint care network



# 2.4. Joint working across services

Coordinated care and good communication across services is essential to ensuring that people with an eating disorder receive the care they need (see <u>NICE Quality Statement 5</u>), to ensure clear access and referral pathways so that all services can work together to prevent gaps in provision and deliver the right care for the person.<sup>4</sup>

Integrated care arrangements across services are essential and should:

- set clear parameters around working relationships, including protocols regarding referrals, assessments, access to treatments, and possible inpatient admissions or intensive care
- use joint or interoperable record systems (digital records) where possible.
- include regular liaison and joint working meetings, including coordinated review meetings, joint training and education opportunities
- be based on a care plan that is co-produced (developed and written with a person and their family, partner or carers; see Section 1.3 and 3.5)
- have clearly established processes for when someone is not ready to engage or refuses treatment (see Section 3.4)

# 3. Delivery of evidence-based treatment, care and support

#### 3.1 Person-centred care

Person-centred care is the foundation of all care provided by a CED service, involving shared decision-making and working collaboratively with the person, their family, partner, carers and support network (as appropriate). People should be given clear information on the service, including how to access an advocate, getting a second opinion, how to make a complaint and how to provide feedback. Professionals should refer to the <a href="Service User Experience in Adult Mental Health guideline">Service User Experience in Adult Mental Health guideline</a> and <a href="Service User Experience in Adult Mental Health services">Services</a>. Health <a href="Services quality standard">Services quality standard</a> on improving people's experience of mental health services.

Informed patient choice is integral to all discussions, particularly regarding options for psychological treatment (see NICE Quality Statement 2)<sup>4</sup>. Some people who may be at high risk may need additional clinical support to understand the need for appropriate treatment to ensure their safety at all times. It is the CED service's responsibility to ensure a choice is informed by making the service user aware of all relevant information. Information and guidance is available for providers and commissioners on <a href="Choice in Mental Health">Choice in Mental Health</a> and information on people's legal rights to <a href="Choice in mental health care">Choice in mental health care</a>.

# 3.2 Accessing treatment, care and support

All CED services should be accessible to people who require care for an eating disorder, with no thresholds or barriers to receiving treatment. The following principles are key:

- Access to care should be equal regardless of whether a person is presenting for the first time or with a long-term condition. When re-presenting, a person should be able to access a CED service at the first sign of a relapse to receive care as soon as possible.
- Decisions on accepting referrals and discharge should never be made based solely on a person's BMI, weight, or frequency of bingeing and purging episodes (NICE guideline

section 1.2.8),<sup>2</sup> but should incorporate the person's goals for treatment and recovery. For example, obesity in the presence of an eating disorder should not prevent a person from receiving support from a CED service.<sup>12</sup>

- If a person is moving to another area and requires ongoing care, then their CED service should proactively contact the CED service in that area to ensure continuity of care. Registration with a GP should not be an essential criterion for access. If someone presenting to a CED service is not registered with a local GP, then facilitating this should be included in their care plan.
- People should receive treatment, care and support as soon as possible. For instance, if a person presents to their GP with a suspected eating disorder, the GP should immediately contact the CED service for advice and follow their recommendations (NICE guideline section 1.2.10).<sup>2</sup> The CED service should aim to maximise access and minimise waits and they may wish to look at work done in Children and Young People's Community Eating Disorder teams where services are tracking access and waiting times. While a person is waiting for treatment, services should consider whether to involve or signpost to VCSE organisations or draw on online resources, local groups or telephone helplines for additional support (see Helpful Resources, part 2).
- Care should be provided in the most appropriate setting to meet a person's needs and should be as accessible as possible. CED services based in rural areas should consider whether care can safely and effectively be delivered:
  - by an outreach team or in an alternative setting, such as a private room in a primary care practice or community service
  - o through digital technologies such as Skype;
  - o or with additional support with transport to access the service may be required.

# 3.3 Assessment and engagement

Assessment should be completed by an experienced clinician within the CED service and it should cover physical health, mental health and social factors. The CED service should liaise with referring agencies to ensure assessments are not unnecessarily repeated.

An assessment should not be based on single measures (such as BMI alone; NICE guideline section 1.2.8)<sup>2</sup>; rather, it should identify the relevant symptoms and behaviours of an eating disorder. The CED service should discuss with their service users, the use of social media and how they can support a person to interact with social media in a positive way.

The outcome of an assessment should result in a shared understanding of the presenting problem or needs. It should be carried out with the person to allow for a collaborative decision about how to effectively address their needs and to develop an agreed care plan. Professionals should refer to NICE guidance (NICE guideline section 1.2)<sup>2</sup> for further criteria for identification and assessment of an eating disorder.

The CED service should be prepared to be met with reluctance to engaging in treatment on the part of a person but should nevertheless make every reasonable effort to engage them, particularly when there is evidence of recent deterioration or severe risk. Responsibility for outreach, follow-up and engaging with people who are reluctant to receive treatment lies with the CED service. In some cases, the CED service may deliver support indirectly by engaging with the person's family, partner, carer or a member of their support network, or else indirectly via other trusted services. Peer support workers can also bolster engagement in treatment among adults with eating disorders. Setting clear timeframes for follow-up by the CED service to check people's readiness for treatment may be useful.

## 3.4 Care plans

Every person that presents to the CED should receive a written care plan following assessment. Care plans should be developing in line with the <u>eating disorders NICE guideline</u> (NG69).<sup>2</sup>, with a recognition that early intervention demonstrates effective outcomes; see NICE <u>Quality Statement 1</u>.<sup>4,15,16</sup> The plan should be co-produced by the person, their family, partner or carer (as appropriate).

The plan can vary in detail depending on the complexity of the case and may include:

- details of all healthcare professionals and services involved, with their roles and responsibilities, including the person's main care coordinator
- how services will work together to provide treatment, care and support
- how the person's family, partner, carer or support network may be involved in their care
- the person's goals for treatment and recovery, including how progress towards these will be measured, and strategies to prevent relapse
- all options for treatment, care and support, such as type of treatment offered, number of sessions expected and where they will receive treatment
- social or environmental factors that are important to the person, such as support for work or education, or engaging in meaningful activities or hobbies
- medical monitoring (blood samples, ECGs), including frequency, plans if the person does not attend tests when expected, the professional responsible for obtaining and acting on the results, and a clear plan for medical monitoring on discharge
- timeframe for reviewing the care plan to determine whether the person's needs are being met or any changes to treatment required
- what the service will do if the person does not attend an appointment
- how the person can access treatment out of hours (if they experience a mental health or physical health emergency)
- how any transitions will be managed
- any requirements for advance care planning where needed (see the Decision-making and Mental Capacity NICE guideline (NG108).<sup>14</sup>
- warning signs of deterioration, clearly outlining strategies for relapse prevention, particularly following a transition<sup>1</sup>. People who have been in a period of recovery but need to return to active treatment should be able to do so without delay and should have this outlined in their care plan.

If a person requires inpatient or intensive day patient treatment, their care plan might also include (see NICE Quality Statement 5)<sup>4</sup>:

- preparing for admission (including frequency and responsibility for monitoring medical and psychiatric risk)
- defined clear objectives and outcomes for inpatient treatment, including potential length of stay
- how a person will be discharged from inpatient care, how they will move back to communitybased care, and what this care should look like.

#### 3.5 Support for families, partners, carers, friends and support networks

Empowering and supporting a person's family, partner, carer, friends and their wider support network is an integral part of service provision, particularly when the person is not ready to receive active treatment. When a person receiving treatment does not want their family involved in their care, CED services should still provide the family with general information on eating disorders and signpost them to appropriate support, resources and services.

Support for families, partners, carers, friends and the wider support network includes:

- valuing and recognising the important role they play in the person's treatment and recovery
- education and information on eating disorders (including links to online resources such as\_ MindEd) and on how they can help a person; this may include training or skills workshops
- providing information on <u>carer assessments</u> so that they can attend to their own needs (see\_NICE guideline section 1.1.10)<sup>2</sup>
- CED services implementing the principles of the <u>Triangle of Care</u>
- helping them maintain their own mental health, physical health and wellbeing
- working with or signposting to local and national organisations, support networks, recovery colleges and VCSE organisations
- empowering them to be part of a person's care and recovery, and including them in meetings (where appropriate)
- appropriate levels of information-sharing, with consent from the person
- having clear discussions about, and making them aware of, the issues around confidentiality.

#### Services should consider:

- the definition of <u>carer</u>, particularly for adults, where a partner, spouse, sibling or close friend may have caring responsibilities
- the support needs of a person who may not have any family members or carers involved, or those who may receive support from friends or others
- the varying needs of people throughout the lifespan, as younger adults will be more dependent on their family for care, whereas older adults may live independently and may not wish their family to be involved.

Further resources for carers and support networks are listed in the Helpful Resources.

# 3.6 Medical monitoring

The ability to comprehensively monitor and manage the physical health of all people with an eating disorder (across all diagnoses and presentations) is an essential function of a CED service (see NICE guideline section 1.10 <sup>2</sup> and Appendix A). A CED service must be equipped to conduct a full medical assessment, including blood tests and ECGs, and receive same-day results to facilitate same-day clinical decision-making.

Medical monitoring needs to be based on local medical monitoring agreements clearly established across the CED service and primary care network, with one consistent protocol agreed on by local commissioners. The protocol should be developed in collaboration with primary care services and clearly outline the responsibilities for each service (Table 2). A shared care pathway for medical monitoring should be produced.

Table 2: Responsibility for medical monitoring		
CED service	Primary care	
<ul> <li>Person is at high medical risk and/or unable to reliably adhere to physical health monitoring in a primary care</li> </ul>	<ul> <li>Person is at moderate risk but recognises their need for health care and seeks it</li> <li>Person is at low medical risk</li> </ul>	
setting	Person is discharged from the CED service	

When responsibility for medical monitoring is assumed by primary care, the limitations of this need to be recognised and mitigated. The CED service should be accessible to provide specialist consultation to primary care to ensure results are interpreted correctly, regardless of whether a person is currently engaging with the CED service. To ensure that the CED service has capacity to reliably provide this, opportunities for upskilling other staff members (such as nurses) should be explored. A CED service that is accessible for consultation will facilitate GPs' safe acceptance of discharges from the CED service and reduce demand on the CED service's resources.

King's College London has published <u>guidance</u><sup>17</sup> on conducting and interpreting medical risk assessment for people with eating disorders, which may provide important insights for GPs and other medical professionals who do not specialise in eating disorders.

#### 3.7 Intensive community treatment

Intensive community treatment focuses on treating the person in their community as an alternative to an inpatient admission. It can also help reduce length of inpatient stay and inpatient costs overall.<sup>18</sup> It should be considered instead of inpatient or intensive day patient treatment, or for step-down support following an admission.

Intensive community treatment may include:

- a brief period of outreach support provided by the CED service
- increased frequency of community treatment to maintain momentum towards progress, including supervised mealtimes and support for families around meals, provided by the CED service for an agreed period of time.

# 3.8 Inpatient and intensive day patient treatment

**Inpatient treatment.** The decision to admit should be made according to clinical need and the person's safety rather than diagnosis (see NICE guideline section 1.11),<sup>2</sup> and should consider available inpatient or community resources.<sup>6</sup> An admission should be as close to home as possible, with clear goals and objectives (including goals for discharge) agreed and set beforehand, and regular reviews to assess whether inpatient care should be continued or stepped down to a less intensive setting.

The CED service should establish joint working protocols across medical and mental health inpatient units to ensure they can provide input and support inpatient staff during an admission. For continuity of care, the CED service should usually remain the lead in providing care, working closely with inpatient staff from the start of the admission to ensure the person receives the appropriate level of treatment, with psychological and social components incorporated into their care.

The type of unit or ward will depend on the person's needs, which setting can effectively meet those and the availability of beds. If there is a high medical risk or comorbid physical health problem, a person may be admitted to a general medical ward, with clear input from the CED service. People who present with high psychiatric risk may be admitted to an adult mental health unit or psychiatric intensive care unit.

**Intensive day patient treatment.** This provides step-down care from inpatient treatment or an alternative to admission <sup>19,20,21,2</sup>. It may be provided by either an inpatient unit or a CED service, at least four to five times a week, and should include support around main meals as well as encouraging people to learn skills and engage in activities that contribute towards their recovery.

As people make progress, the frequency of day patient treatment should be reviewed and decreased to ensure an appropriate step-down to community treatment. Integrated working across day patient and CED services can help support people to live in the community and prevent relapse or readmission.

Commissioners and providers should refer to <u>NHS England's service specifications for adult eating disorders for inpatient and intensive day patient treatment</u> (these do not cover community eating disorder services commissioned by CCGs).

## 3.9 Managing transitions

Effective management of transitions is critical to ensuring good quality care and should adhere to principles below. Young people moving away from home or attending university/college (incl FE colleges) for the first time are particularly vulnerable (see Appendix F for recommendations on supporting students).

- Transition protocols (see <u>NICE Quality Statement 6</u>)<sup>4</sup> should be in place to ensure good communication between services to avoid inconsistent messages or management approaches. This should be based on a transition plan that includes risk assessment and monitoring, and an agreed next appointment with the CED team or with the person's allocated care coordinator.
- For geographical transitions, CED services should work closely with primary care
  providers, CED services in other areas and university mental health services to remove
  gaps in care and delays in treatment that tend to occur when a person moves to a new
  area and needs to register with a new GP. Transitions should be seamless, with no
  gaps in support or quality of provision. People should be seen by the new CED service
  without delay.
- For age-based transitions, the CED service should work with the CYP-CED service for a minimum of 6 months before the planned transition to ensure a seamless care pathway (see NICE guidance on <u>Transition from Children's to Adult's Services</u>).<sup>24</sup> The parents or carers should be provided with information and advice around the young person's transition, given the change in their rights and role when a young person enters adult services. When a person first presents to a CYP-CED service within 6 months of typical transition age, the CED service should be involved in their initial assessment. For further information on transitions, commissioners and providers should refer to NICE guidance on <u>Transition Between Inpatient Mental Health Settings and Community or Care Home Settings</u>, MARSIPAN Managing <u>Transitions When the Patient has an Eating Disorder</u>

#### 3.10 Managing comorbid conditions

When managing comorbid mental health and physical health problems, the CED service will need to work with the person to identify their goals for treatment and collaborate with other services to provide integrated care (see NICE guideline section 1.8).<sup>2</sup>

The person's level of need may require input from multiple services at the same time. An integrated rather than sequential approach should be taken, with careful thought given to which service should be the lead in this process to ensure continuity of care. Having a comorbid condition should not be a reason for delaying or rejecting someone for treatment.

Continued community treatment for specific conditions, based on the relevant NICE guidance, should always be the aim. Services will need to pay particular regard to supporting people with the following:

**Diabetes.** Diabetes is a significant comorbid physical health problem that needs to be monitored and treated appropriately, with collaborative input from diabetes teams. Staff working across both CED and inpatient or intensive day patient services may require further training and upskilling to support people with diabetes effectively.

"Diabulimia". Diabulimia is a condition where people with diabetes and an eating disorder restrict their insulin intake to lose weight. This is a serious and emerging problem that in the most severe cases can be life-threatening. <a href="NHS">NHS</a> <a href="England recently announced">England recently announced</a> (February 2019) pilot services that will provide joined-up treatment for diabetes and mental health.

**Mental health problems.** Comorbid mental health problems, such as depression and anxiety, are common in people with eating disorders; obsessive—compulsive disorder may be more prevalent in those with anorexia nervosa.<sup>27</sup> Consideration of other comorbid conditions, such as autism, borderline personality disorder or substance misuse is also necessary, as there may be ongoing risk issues and a need to adapt treatment.

# 3.11 Routine measurement of progress and outcomes

Routine outcome measurement should be in place consistently across CED and inpatient or intensive day patient services on three levels.

- 1. **Individual level:** helps to empower the person, inform on progress towards their goals, monitor their symptoms and inform clinical practice
- 2. **Service level:** used to assess people's experience of care to monitor service provision and quality of care
- 3. **Population level:** can be used to monitor the uptake of the service in the area, add to local prevalence data and compare to national data.

See Appendix E for further information on using outcome measures, including a list of measures for CED services.

# 3.12 Advancing mental health equality

Reducing inequalities is best achieved through: co-production (see Section 1.3); specific training and supervision for staff; and the collaboration of national, regional and local commissioners.

There are specific inequalities within eating disorder services, which require focused attention. For example, eating disorders in males and transgender individuals may not be recognised or clearly identified, which may lead to difficulties or delays in accessing appropriate treatment.

CED services can advance mental health equality by:

- ensuring appropriate facilities are provided for people of all genders which is clearly right to ensure men and people of other identities (including people who are transgender and who identify as non-binary) can all access services.
- recognising that transgender and non-binary people may experience body dysmorphic issues that are related to their gender identity rather than their eating disorder, <sup>28</sup> and being mindful of and sensitive to this distinction.

Further information can be found in Appendix H of the Helpful Resources.

# 4. . Definitions of terms and abbreviations

Table 3: Abbreviations			
Abbreviation	Full term	Abbreviation	Full term
ВМІ	Body mass index	MARSIPAN	Management of Really Sick Patients with Anorexia Nervosa
CCG	Clinical commissioning group	MHSDS	Mental Health Services Data Set
CCQI	College Centre for Quality Improvement	NCCMH	National Collaborating Centre for Mental Health
CED	Community eating disorder(s)	NICE	National Institute for Health and Care Excellence
CYP-CED	Children and young people's eating disorder (services)	OSFED	Other specified feeding and eating disorders
ECG	Electrocardiogram	PHSO	Parliamentary and Health Service Ombudsman
GMC	General Medical Council	VCSE	Voluntary, community and social enterprise sector
GP	General practitioner		

Table 4: Definit	Table 4: Definitions of terms	
Term	Definition	
Carer	Anyone who cares for a partner, family member, friend or other person in need of support and assistance with activities of daily living. Carers may be paid or unpaid and include those who care for people with mental health problems, long-term physical health conditions and disabilities.	
Person-centred care	Flexible care based on the need of the person rather than the service. A person is: treated with dignity, compassion and respect; offered coordinated and personalised support, care or treatment; and supported to recognise and develop their strengths and abilities, to enable them to live as independent and fulfilling a life as possible.	
Support network	A group of people, an organisation or a person who provides emotional and/or practical support to someone in need. A support network can be made up of the person's partner, nominated person, friends, family members, parents, siblings, peers, volunteers, health and social care professionals or supportive online forums and social networking sites.	
Transition	The planning process around and handling of transfers of care between care settings and/or location, including the initial planning, the transfer itself and the support provided throughout.	
Urgent	When a person may be at high risk (physical or mental health risk that threatens their life, long-term health or the safety of others) and they require an immediate response from services.	

#### 5. How was this guide developed?

In response to the PHSO report, <sup>1</sup> an Expert Reference Group (ERG) was convened by NHS England to address the specific recommendation for NHS England to review the existing quality and availability of services to achieve parity with children and young people's eating disorder services.

The National Collaborating Centre for Mental Health (NCCMH) was then commissioned to develop this guidance. The ERG included people with expertise in the area of eating disorders, including those with experience of using services, and those from clinical, academic and commissioning backgrounds. A separate reference group was convened with people with experience of receiving treatment for an eating disorder to further develop the recommendations within this guide.

The recommendations in this guidance were developed based on NICE guidelines and quality standards, evidence of positive practice from published literature and existing services, and consensus from the ERG.

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# Special acknowledgements

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# **Services visited**

Eating Disorder Services visited
Dorset Children, Young People and Adult Eating Disorder Service
Hampshire Community Eating Disorder Service
FREED and Adult Eating Disorder Service, South London and Maudsley NHS Foundation Trust

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