

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health and social care directorate

### Quality standards and indicators

#### Briefing paper

**Quality standard topic:** Eating disorders

**Output:** Prioritised quality improvement areas for development.

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## 1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for eating disorders. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

### 1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

### 1.2 Development source

The key development source referenced in this briefing paper is:

- [Eating disorders: recognition and treatment](#) (2017) NICE guideline NG69.

## 2 Overview

### 2.1 Focus of quality standard

This quality standard will cover assessment, treatment, monitoring and inpatient care for children, young people and adults with an eating disorder.

### 2.2 Definition<sup>1</sup>

Eating disorders have been described as “a persistent disturbance of eating behaviour or behaviour intended to control weight, which significantly impairs physical health or psychosocial functioning” (Fairburn et al., 2002)<sup>2</sup>. More recent definitions have reduced the emphasis on ‘intent’. Behaviours include:

- restriction of dietary intake
- overeating with a sense of loss of control
- compensatory behaviours (e.g., vomiting, exercise, laxative abuse).

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<sup>1</sup> Definition section from [Eating Disorders: recognition and treatment- NICE full guideline \(2017\)](#)

<sup>2</sup> Wilson GT, Fairburn CC, Agras WS, Walsh BT, Kraemer H (2002) [Cognitive-behavioral therapy for bulimia nervosa: time course and mechanisms of change.](#)

These behaviours are accompanied by cognitive disturbances (e.g., overvaluation of weight; body image disturbance), emotional triggers and consequences (e.g., anxiety, shame) and social difficulties (e.g., isolation).

The majority of individuals with eating disorders (80-85%) are not underweight (Fairburn et al., 2003)<sup>3</sup>. However, regardless of weight status, patients with eating disorders are at increased physical risk as a result of malnutrition (e.g., cardiac problems; bone deterioration), binge eating (e.g., physical damage; complications of excess weight, such as diabetes), purging (e.g., electrolyte imbalance) and mood (e.g., suicidality) (Treasure et al., 2010).<sup>4</sup>

### **2.3 Incidence and prevalence<sup>5</sup>**

There are over 700,000 individuals in the UK with an eating disorder (Beating Eating Disorders Charity-BEAT, 2015). While the prevalence is relatively stable, the number of cases identified in clinical settings is increasing as clinicians become more aware of these disorders and patients come forward more readily (Currin et al., 2005<sup>6</sup>; Soundy et al., 1995<sup>7</sup>). However, many cases remain unidentified.

About 90% of eating disorder cases are female and most are of normal weight or above (only about 15-20% meet criteria for anorexia nervosa) (BEAT, 2015<sup>8</sup>; Fairburn and Harrison, 2003<sup>9</sup>; Soundy et al., 1995<sup>7</sup>). Some groups are at greater risk of developing eating disorders (e.g., those who work or study in areas where there is a strong focus on physical appearance, such as dancers, models or athletes). Others are at particularly high risk of complications if they develop an eating disorder (e.g., those with type 1 diabetes).

It is acknowledged that eating disorders can develop at any age the majority of eating disorders have their origins in adolescence and young adulthood, although a substantial number of cases begin at younger or older ages. Anorexia nervosa commonly develops around the ages of 16-17, while bulimia nervosa develops at 18-19 and binge eating disorder appears later in life, usually between the ages of 30-40.<sup>8</sup>

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<sup>3</sup> Fairburn CG, Cooper Z, Shafran R (2003) [Cognitive behaviour therapy for eating disorders: a "transdiagnostic" theory and treatment.](#)

<sup>4</sup> Treasure J, Claudino AM, Zucker N (2010) [Eating disorders](#)

<sup>5</sup> Incidence, prevalence and management sections from [Eating Disorders: recognition and treatment- NICE full guideline \(2017\)](#)

<sup>6</sup> Currin L, Schmidt U, Treasure J, Jick H (2005) [Time trends in eating disorder incidence](#)

<sup>7</sup> Soundy T, Lucas A, Suman V, Melton L (1995) [Bulimia nervosa in Rochester, Minnesota from 1980 to 1990](#)

<sup>8</sup> BEAT (2015) [The costs of eating disorders- social, health and economic impacts](#)

<sup>9</sup> Fairburn CG, Harrison PJ (2003) [Eating disorders](#)

## **2.4      *Management*<sup>5</sup>**

Risk management should always be seen as the first consideration in managing eating disorders.

There is wide variation in how eating disorders are treated and managed in the NHS. This variation can be seen across the whole care pathway from the initial referral, through primary psychological services, outpatient child and young people mental health services (CAMHS), as well as across adult services. Some teams provide generic support, while others offer more specialist input. This variation is also applicable to inpatient services, with some service users being treated in specialist eating disorder units and others being admitted to generic mental health units.

Significant geographical inconsistencies also exist, with different areas providing widely contrasting services. This pattern of geographical difference is likely to be influenced by national funding variations as well as differences in referral criteria to specialist services. For example, NHS England Specialised Commissioning has contracts with both NHS and private inpatient units, with admission criteria largely dependent on where the service user lives. Consequently, people can sometimes be admitted to units geographically distant from both their home and community-based services.

## **2.5      *National outcome frameworks***

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1 [NHS outcomes framework 2016–17](#)**

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	<p><b>Overarching indicators</b></p> <p>1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare</p> <p>i Adults ii Children and young people</p> <p>i Males ii Females</p> <p><b>Improvement areas</b></p> <p><b>Reducing premature mortality in people with mental illness</b></p> <p>1.5 i Excess under 75 mortality rate in adults with serious mental illness*</p> <p>ii Excess under 75 mortality rate in adults with common mental illness*</p> <p>iii Suicide and mortality from injury of undetermined intent among people with recent contact from NHS services**</p>
2 Enhancing quality of life for people with long-term conditions	<p><b>Overarching indicator</b></p> <p>2 Health-related quality of life for people with long-term conditions**</p> <p><b>Improvement areas</b></p> <p><b>Ensuring people feel supported to manage their condition</b></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><b>Improving functional ability in people with long-term conditions</b></p> <p>2.2 Employment of people with long-term conditions*. **</p> <p><b>Enhancing quality of life for carers</b></p> <p>2.4 Health-related quality of life for carers**</p> <p><b>Enhancing quality of life for people with mental illness</b></p> <p>2.5 i Employment of people with mental illness**</p> <p>ii Health-related quality of life for people with mental illness**</p>
3 Helping people to recover from episodes of ill health or following injury	<p><b>Overarching indicators</b></p> <p><b>Improvement areas</b></p> <p><b>Improving outcomes from planned treatments</b></p> <p>3.1 Total health gain as assessed by patients for elective procedures</p> <p>ii Psychological therapies</p> <p>iii Recovery in quality of life for patients with mental illness</p>
4 Ensuring that people have a positive experience of care	<p><b>Overarching indicators</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>ii GP Out-of-hours services</p> <p>4b Patient experience of hospital care</p>

	<p><i>4c Friends and family test</i>  <i>4d Patient experience characterised as poor or worse</i>  <i>i Primary care</i>  <i>ii Hospital care</i></p> <p><b>Improvement areas</b>  <b>Improving people’s experience of outpatient care</b>  4.1 Patient experience of outpatient services  <b>Improving hospitals’ responsiveness to personal needs</b>  4.2 Responsiveness to inpatients’ personal needs  <b>Improving access to primary care services</b>  4.4 Access to i GP services  <b>Improving experience of healthcare for people with mental illness</b>  <i>4.7 Patient experience of community mental health services</i>  <b>Improving children and young people’s experience of healthcare</b>  <i>4.8 Children and young people’s experience of inpatient services</i>  <b>Improving people’s experience of integrated care</b>  4.9 <i>People’s experience of integrated care**</i></p>
<p>5 Treating and caring for people in a safe environment and protecting them from avoidable harm</p>	<p><b>Overarching indicators</b>  <i>5a Deaths attributable to problems in healthcare</i>  <i>5b Severe harm attributable to problems in healthcare</i></p> <p><b>Improvement areas</b>  <b>Improving the culture of safety reporting</b>  5.6 Patient safety incidents reported</p>
<p><b>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</b>  * Indicator is shared  ** Indicator is complementary  Indicators in italics in development</p>	

**Table 2 [Public health outcomes framework for England, 2016–2019](#)**

<b>Domain</b>	<b>Objectives and indicators</b>
4 Healthcare public health and preventing premature mortality	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p><b>Indicators</b></p> <p>4.09 Excess under 75 mortality rate in adults with serious mental illness*</p> <p>4.10 Suicide rate**</p> <p>4.11 Emergency readmissions within 30 days of discharge from hospital*</p>
<p><b><i>Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework</i></b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

## **3 Summary of suggestions**

### **3.1 Responses**

In total 11 stakeholders responded to the 2-week engagement exercise 2/8/2017-16/8/2017.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the committee.

NHS Improvement's patient safety division submitted comments for this topic during stakeholder engagement, which are summarised in this paper and can be found in full in appendix 2.

Full details of all the suggestions provided are given in appendix 2 for information.



**Table 3 Summary of suggested quality improvement areas**

Suggested area for improvement	Stakeholders
<p><b>Identification and assessment</b></p> <ul style="list-style-type: none"> <li>• Initial assessments in primary and secondary mental health care</li> <li>• Referral</li> </ul>	<ul style="list-style-type: none"> <li>• BDAMHSG, BEAT, SCM3, SCM4, SCM5, SCM6</li> <li>• BDAMHSG</li> </ul>
<p><b>Treating eating disorders</b></p> <ul style="list-style-type: none"> <li>• Treating anorexia nervosa</li> <li>• Psychological treatment for anorexia nervosa, binge eating disorder and bulimia nervosa in adults</li> <li>• Psychological treatment for anorexia nervosa and bulimia nervosa in children and young people</li> </ul>	<ul style="list-style-type: none"> <li>• BDAMHSG, BEAT, SCM3, SCM5</li> <li>• SCM1, SCM2, TEWVNHSFT</li> <li>• AFTSP, SCM1</li> </ul>
<p><b>Physical health assessment and monitoring for all eating disorders</b></p> <ul style="list-style-type: none"> <li>• Physical and mental health comorbidities</li> <li>• Physical health assessment and monitoring for all eating disorders</li> <li>• Assessment and monitoring of physical health in anorexia nervosa</li> </ul>	<ul style="list-style-type: none"> <li>• SCM2, SCM4</li> <li>• BDAMHSG, SCM2</li> <li>• BDAMHSG, SCM5, TEWVNHSFT</li> </ul>
<p><b>Access and coordinated care</b></p> <ul style="list-style-type: none"> <li>• Improving access to services</li> <li>• Coordination of care for people with an eating disorder</li> <li>• Inpatient and day patient treatment</li> <li>• Working with family members and carers</li> </ul>	<ul style="list-style-type: none"> <li>• BDAMHSG, SCM2, SCM4, TEWVNHSFT, SCM6</li> <li>• BEAT, SCM3, SCM5, SCM6</li> <li>• SCM2</li> <li>• BEAT</li> </ul>
<p><b>Additional areas</b></p> <ul style="list-style-type: none"> <li>• Access to specialist registered dietitian within community eating disorder multidisciplinary teams</li> <li>• Diabetes</li> <li>• MARSIPAN regional hubs</li> <li>• Occupational therapy</li> <li>• Psychological interventions with no current randomised controlled trials</li> <li>• Training and competencies</li> </ul>	<ul style="list-style-type: none"> <li>• BDAMHSG</li> <li>• NHSE</li> <li>• SCM5</li> <li>• TEWSNHSFT</li> <li>• TEWSNHSFT</li> <li>• BEAT, NHSI, SCM3</li> </ul>
<p>AFTSP, Association for Family Therapy and Systemic Practice            BDAMHSG, British Dietetic Association Mental Health Specialist Group            BEAT, Beating Eating Disorders Charity            NHSE, NHS England, National Clinical Director for Obesity and Diabetes            NHSI, NHS Improvement, Patient Safety Team            SCM, Specialist Committee Member            TEWSNHSFT, Tees, Esk and Wear Valleys NHS Foundation Trust</p>	

### **3.2      *Identification of current practice evidence***

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1159 papers were identified for eating disorders. In addition, 20 papers were suggested by stakeholders at topic engagement and 4 papers internally at project scoping.

Of these papers, 15 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

## 4 Suggested improvement areas

### 4.1 Identification and assessment

#### 4.1.1 Summary of suggestions

##### Identification and initial assessments in primary and secondary mental health care

A stakeholder suggested that eating disorders can be present in a range of settings based on signs and symptoms therefore raised awareness is needed. Early interventions were supported to potentially reduce the need for more intensive treatments in the future and the need for rapid access to evidence-based treatment to increase treatment effectiveness.

##### Referral

A stakeholder suggested that referrals should be made to a multidisciplinary community-based, age-appropriate eating disorder service, for further assessment or intervention, in a prompt and timely manner to ensure that the most appropriate treatment takes place as quickly as possible.

#### 4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

**Table 4 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Identification and initial assessments in primary and secondary mental health care	<b>Identification and initial assessments in primary and secondary mental health care</b> NICE NG69 Recommendations 1.2.1-1.2.3
Referral	<b>Referral</b> NICE NG69 Recommendation 1.2.10

## **Identification and initial assessments in primary and secondary mental health care**

### NICE NG69 Recommendation 1.2.1

People with eating disorders should be assessed and receive treatment at the earliest opportunity.

### NICE NG69 Recommendation 1.2.2

Early treatment is particularly important for those with or at risk of severe emaciation and such patients should be prioritised for treatment.

### NICE NG69 Recommendation 1.2.3

Be aware that eating disorders present in a range of settings, including:

- primary and secondary health care (including acute hospitals)
- social care
- education
- work.

## **Referral**

### NICE NG69 Recommendation 1.2.10

If an eating disorder is suspected after an initial assessment, refer immediately to a community-based, age-appropriate eating disorder service for further assessment or treatment.

### **4.1.3 Current UK practice**

## **Identification and initial assessments in primary and secondary mental health care**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience

## **Referral**

The Royal College of Psychiatrists (2012)<sup>10</sup> examined specialist service provision including the NHS, the private sector and also paediatric and general psychiatric

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<sup>10</sup> Royal College of Psychiatrists (2012) [Eating disorders in the UK: service distribution, service development and training](#)

services for the full age range of people with eating disorders. It was concluded that this is limited in many UK regions with only approximately half of health authorities having a specialist service within their area, and under two-thirds having a consultant psychiatrist with at least three sessions on eating disorders.

BEAT (2013)<sup>11</sup> survey on waiting times and access to treatment concluded 331 of the 471 respondents had received outpatient treatment. Of this group:

- Thirty percent had to wait longer than 18 weeks to access outpatient treatment and twenty-six percent had to wait 6 months or longer from referral to start of outpatient treatment, with eight percent waiting a year or more and some as long as 2 years.
- Forty percent were told that their BMI wasn't 'low enough to access treatment quickly'.
- Forty-two percent who had been diagnosed with bulimia and had been referred to outpatient treatment had to wait longer than 18 weeks to begin treatment
- Fifty-eight percent were not kept in contact with by the treatment service which they were referred to, whilst they waited for treatment.

The 1 January and 31 March 2017 data<sup>12</sup> indicates that 1,645 new referrals for people aged under 19 with eating disorder issues were received.

#### **4.1.4 Resource impact assessment**

No significant resource impact expected.

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<sup>11</sup> BEAT (2013) [Waiting Times for treatment](#)

<sup>12</sup> NHS Digital (2017) [Mental Health Services Monthly Statistics: Final March 2017](#)

## **4.2      *Treating eating disorders***

### **4.2.1    Summary of suggestions**

#### **Treating anorexia nervosa**

A stakeholder highlighted the need for stronger emphasis on achieving weight gain as the most important target for recovery. A multidisciplinary approach for treating anorexia nervosa is also needed due to the complexity of this eating disorder including dietetics and psychiatry as this is highly variable across the UK.

#### **Psychological treatment for anorexia nervosa, binge eating disorder and bulimia nervosa in adults**

Stakeholders highlighted the importance of psychological therapies for eating disorders in adults.

A stakeholder supported the use of Specialist Supportive Clinical Management (SSCM) for people with eating disorders as a clear care pathway with a range of specialist health professionals. SSCM should be flexible and tailored to the individual, enabling a strong therapeutic relationship to support change.

A stakeholder supported guided self-help programmes for outpatient adults with bulimia nervosa and binge eating disorders which should be delivered by using a stepped care treatment model.

A stakeholder highlighted the importance of engagement for people with moderate to severe eating disorders such as bulimia nervosa. This was felt to be crucial for helping people to progress towards improvement and recovery. as currently both engagement levels and engagement interventions vary across UK providers.

#### **Psychological treatment for anorexia nervosa and bulimia nervosa in children and young people**

Stakeholders highlighted the importance of psychological therapies for anorexia and bulimia nervosa in children and young people.

In terms of improving treatment effectiveness, a stakeholder favoured family therapies for young people with eating disorders above individual therapy. Availability of family therapists was also reported as variable within the UK.

### **4.2.2    Selected recommendations from development source**

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

**Table 5 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Treating anorexia nervosa	<b>Treating anorexia nervosa</b> NICE NG69 Recommendations 1.3.1 and 1.3.2
Psychological treatment for anorexia nervosa, binge eating disorder and bulimia nervosa in adults	<b>Psychological treatment for anorexia nervosa, binge eating disorder and bulimia nervosa in adults</b> NICE NG69 Recommendations 1.3.7, 1.4.2, 1.5.3 and 1.5.5
Psychological treatment for anorexia nervosa and bulimia nervosa in children and young people	<b>Psychological treatment for anorexia nervosa and bulimia nervosa in children and young people</b> NICE NG69 Recommendations 1.3.11, 1.3.16, 1.3.17, 1.5.6, 1.5.7 and 1.5.10

### **Treating anorexia nervosa**

#### NICE NG69 Recommendation 1.3.1

Provide support and care for all people with anorexia nervosa in contact with specialist services, whether or not they are having a specific intervention. Support should:

- include psychoeducation about the disorder
- include monitoring of weight, mental and physical health, and any risk factors
- be multidisciplinary and coordinated between services
- involve the person's family members or carers (as appropriate).

#### NICE NG69 Recommendation 1.3.2

When treating anorexia nervosa, be aware that:

- helping people to reach a healthy body weight or BMI for their age is a key goal and
- weight gain is key in supporting other psychological, physical and quality of life changes that are needed for improvement or recovery.

### **Psychological treatment for anorexia nervosa in adults**

#### NICE NG69 Recommendation 1.3.7

SSCM for adults with anorexia nervosa should:

- typically consist of 20 or more weekly sessions (depending on severity)

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- assess, identify, and regularly review key problems
- aim to develop a positive relationship between the person and the practitioner
- aim to help people recognise the link between their symptoms and their abnormal eating behaviour
- aim to restore weight
- provide psychoeducation, and nutritional education and advice
- include physical health monitoring
- establish a weight range goal
- encourage reaching a healthy body weight and healthy eating
- allow the person to decide what else should be included as part of their therapy.

### **Psychological treatment for binge eating disorder in adults**

#### NICE NG69 Recommendation 1.4.2

Offer a binge-eating-disorder-focused guided self-help programme to adults with binge eating disorder

### **Psychological treatment for bulimia nervosa in adults**

#### NICE NG69 Recommendation 1.5.3

Bulimia-nervosa-focused guided self-help programmes for adults with bulimia nervosa should:

- use cognitive behavioural self-help materials for eating disorders
- supplement the self-help programme with brief supportive sessions (for example 4 to 9 sessions lasting 20 minutes each over 16 weeks, running weekly at first).

#### NICE NG69 Recommendation 1.5.5

Individual CBT-ED for adults with bulimia nervosa should:

- typically consist of up to 20 sessions over 20 weeks, and consider twice-weekly sessions in the first phase
- in the first phase focus on:
  - engagement and education
  - establishing a pattern of regular eating, and providing encouragement, advice and support while people do this



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- follow by addressing the eating disorder psychopathology (for example, the extreme dietary restraint, the concerns about body shape and weight, and the tendency to binge eat in response to difficult thoughts and feelings)
- towards the end of treatment, spread appointments further apart and focus on maintaining positive changes and minimising the risk of relapse
- if appropriate, involve significant others to help with one-to-one treatment

### **Psychological treatment for anorexia nervosa in children and young people**

#### NICE NG69 Recommendation 1.3.11

Anorexia-nervosa-focused family therapy for children and young people with anorexia nervosa should:

- typically consist of 18–20 sessions over 1 year
- review the needs of the person 4 weeks after treatment begins and then every 3 months, to establish how regular sessions should be and how long treatment should last
- emphasise the role of the family in helping the person to recover
- not blame the person or their family members or carers
- include psychoeducation about nutrition and the effects of malnutrition
- early in treatment, support the parents or carers to take a central role in helping the person manage their eating, and emphasise that this is a temporary role
- in the first phase, aim to establish a good therapeutic alliance with the person, their parents or carers and other family members
- in the second phase, support the person (with help from their parents or carers) to establish a level of independence appropriate for their level of development
- in the final phase:
  - focus on plans for when treatment ends (including any concerns the person and their family have) and on relapse prevention
  - address how the person can get support if treatment is stopped.

#### NICE NG69 Recommendation 1.3.16

Individual CBT-ED for children and young people with anorexia nervosa should:

- typically consist of up to 40 sessions over 40 weeks, with:

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- twice-weekly sessions in the first 2 or 3 weeks
- 8–12 additional brief family sessions with the person and their parents or carers (as appropriate)
- in family sessions and in individual sessions, include psychoeducation about nutrition and the effects of malnutrition
- in family sessions:
  - identify anything in the person's home life that could make it difficult for them to change their behaviour, and find ways to address this
  - discuss meal plans
- aim to reduce the risk to physical health and any other symptoms of the eating disorder
- encourage reaching a healthy body weight and healthy eating
- cover nutrition, relapse prevention, cognitive restructuring, mood regulation, social skills, body image concern and self-esteem
- create a personalised treatment plan based on the processes that appear to be maintaining the eating problem
- take into account the person's specific development needs
- explain the risks of malnutrition and being underweight
- enhance self-efficacy
- include self-monitoring of dietary intake and associated thoughts and feelings
- include homework, to help the person practice what they have learned in their daily life
- address how the person can get support if treatment is stopped.

### NICE NG69 Recommendation 1.3.17

Adolescent-focused psychotherapy for anorexia nervosa for children and young people should:

- typically consist of 32–40 individual sessions over 12–18 months, with:
  - more regular sessions early on, to help the person build a relationship with the practitioner and motivate them to change their behaviour
  - 8–12 additional family sessions with the person and their parents or carers (as appropriate)
- review the needs of the person 4 weeks after treatment begins and then every 3 months, to establish how regular sessions should be and how long treatment should last
- in family sessions and in individual sessions, include psychoeducation about nutrition and the effects of malnutrition
- focus on the person's self-image, emotions and interpersonal processes, and how these affect their eating disorder
- develop a formulation of the person's psychological issues and how they use anorexic behaviour as a coping strategy

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- address fears about weight gain, and emphasise that weight gain and healthy eating is a critical part of therapy
- find alternative strategies for the person to manage stress
- in later stages of treatment, explore issues of identity and build independence
- towards end of treatment, focus on transferring the therapy experience to situations in everyday life
- in family sessions, help parents or carers support the person to change their behaviour
- address how the person can get support if treatment is stopped.

### **Psychological treatment for bulimia nervosa in children and young people**

#### NICE NG69 Recommendation 1.5.6

Offer bulimia-nervosa-focused family therapy (FT-BN) to children and young people with bulimia nervosa.

#### NICE NG69 Recommendation 1.5.7

FT-BN for children and young people with bulimia nervosa should:

- typically consist of 18–20 sessions over 6 months
- establish a good therapeutic relationship with the person and their family members or carers
- support and encourage the family to help the person recover
- not blame the person, their family members or carers
  - include information about:
    - regulating body weight
    - dieting
    - the adverse effects of attempting to control weight with self-induced vomiting, laxatives or other compensatory behaviours
- use a collaborative approach between the parents and the young person to establish regular eating patterns and minimise compensatory behaviours
- include regular meetings with the person on their own throughout the treatment
- include self-monitoring of bulimic behaviours and discussions with family members or carers
- in later phases of treatment, support the person and their family members or carers to establish a level of independence appropriate for their level of development
- in the final phase of treatment, focus on plans for when treatment ends (including any concerns the person and their family have) and on relapse prevention.

### NICE NG69 Recommendation 1.5.10

Individual CBT-ED for children and young people with bulimia nervosa should:

- typically consist of 18 sessions over 6 months, with more frequent sessions early in treatment
- include up to 4 additional sessions with parents or carers
- initially focus on the role bulimia nervosa plays in the person's life and on building motivation to change
- provide psychoeducation about eating disorders and how symptoms are maintained, while encouraging the person to gradually establish regular eating habits
- develop a case formulation with the person
- teach the person to monitor their thoughts, feelings and behaviours
- set goals and encourage the person to address problematic thoughts, beliefs and behaviours with problem-solving
- use relapse prevention strategies to prepare for and mitigate potential future setbacks
- in sessions with parents and carers, provide education about eating disorders, identify family factors that stop the person from changing their behaviour, and discuss how the family can support the person's recovery.

#### **4.2.3 Current UK practice**

##### **Treating anorexia nervosa**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience

##### **Psychological treatment for anorexia nervosa in adults, young people and children**

Royal College of Psychiatrists (2012)<sup>13</sup> reported the most common therapeutic approaches for anorexia nervosa used by services were:

- individual cognitive-behavioural therapy (84%)
- nutritional advice and monitoring (82%)
- family-based treatment (77%).

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<sup>13</sup> Royal College of Psychiatrists (2012) [Eating disorders in the UK: service distribution, service development and training](#)

### **Psychological treatment for binge eating disorder in adults**

Royal College of Psychiatrists (2012)<sup>20</sup> reported the most common therapeutic approaches for binge eating disorder used by services were:-

- self-help interventions (58%)
- nutritional advice and monitoring (54%)
- individual cognitive behavioural therapy (54%).

### **Psychological treatment for bulimia nervosa in adults, young people and children**

Royal College of Psychiatrists (2012)<sup>20</sup> reported the most common therapeutic approaches for bulimia nervosa used by services were:

- individual CBT (79%)
- self-help literature (67%)
- selective serotonin-reuptake inhibitors (SSRIs) (65%).

## **4.2.4 Summary of suggestions**

### **Resource impact assessment**

No significant resource impact expected from psychological treatments for bulimia nervosa and anorexia nervosa. Treatments are already part of current practice although practice varies across the country.

There may be costs in relation to treatments for binge eating in adults. Many services do not provide psychological treatments for binge eating disorder. Where they exist they do not offer guided self-help, group CBT-ED or individual CBT-ED. Costs depend on the model of service and package of care and types of interventions discussed and agreed with the service user at a local level.

### **4.3      *Physical health assessment, monitoring and management for all eating disorders***

#### **4.3.1     Summary of suggestions**

##### **Physical and mental health comorbidities**

A stakeholder highlighted the importance of physical health monitoring and management of health co-morbidities in the community setting.

A stakeholder highlighted that eating disorder specialists and other healthcare teams should collaborate to support effective treatment and management of physical and mental health comorbidities.

In terms of outcome monitoring, a stakeholder reported that there is potentially wide variability across services. They felt improved monitoring would enable identification in patients who are not responding to treatment and treatment packages would be amended accordingly.

##### **Assessment and monitoring of physical health in anorexia nervosa**

Stakeholders supported the need for annual GP health checks to ensure that people with anorexia nervosa are not in crisis and avoiding contact. This in turn will help prevent avoidable patient harm and long term hospital stays.

#### **4.3.2     Selected recommendations from development source**

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

**Table 6 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Physical and mental health comorbidities	<b>Physical and mental health comorbidities</b> NICE NG69 Recommendations 1.8.1 and 1.8.2
Physical health assessment and monitoring for all eating disorders	<b>Physical health assessment and monitoring for all eating disorders</b> NICE NG69 Recommendation 1.10.2
Assessment and monitoring of physical health in anorexia nervosa	<b>Assessment and monitoring of physical health in anorexia nervosa</b> NICE NG69 Recommendation 1.10.10

### **Physical and mental health comorbidities**

#### NICE NG69 Recommendation 1.8.1

Eating disorder specialists and other healthcare teams should collaborate to support effective treatment of physical or mental health comorbidities in people with an eating disorder.

#### NICE NG69 Recommendation 1.8.2

When collaborating, teams should use outcome measures for both the eating disorder and the physical and mental health comorbidities, to monitor the effectiveness of treatments for each condition and the potential impact they have on each other.

### **Physical health assessment and monitoring for all eating disorders**

#### NICE NG69 Recommendation 1.10.2

Assess whether ECG monitoring is needed in people with an eating disorder, based on the following risk factors:

- rapid weight loss
- excessive exercise
- severe purging behaviours, such as laxative or diuretic use or vomiting
- bradycardia
- hypotension
- excessive caffeine (including from energy drinks)

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- prescribed or non-prescribed medications
- muscular weakness
- electrolyte imbalance
- previous abnormal heart rhythm

### **Assessment and monitoring of physical health in anorexia nervosa**

#### NICE NG69 Recommendation 1.10.10

GPs should offer a physical and mental health review at least annually to people with anorexia nervosa who are not receiving ongoing treatment for their eating disorder.

The review should include:

- weight or BMI (adjusted for age if appropriate)
- blood pressure
- relevant blood tests
- any problems with daily functioning
- assessment of risk (related to both physical and mental health)
- an ECG, for people with purging behaviours and/or significant weight changes
- a discussion of treatment options.

### **4.3.3 Current UK practice**

#### **Physical and mental health comorbidities**

Royal College of Psychiatrists (2012)<sup>14</sup> reported that outcome monitoring was undertaken by 75% of participating services however outcome measures varied widely with a mixture of eating disorder-specific and generic measures being employed.

#### **Physical health assessment, monitoring and management for all eating disorders**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience

### **Assessment and monitoring of physical health in anorexia nervosa**

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<sup>14</sup> Royal College of Psychiatrists (2012) [Eating disorders in the UK: service distribution, service development and training](#)



Currin et al (2007)<sup>15</sup> assessed the provision of UK eating disorders services in primary care and concluded:

- only 4% of GPs reported using a published guideline or protocol for managing ED
- between 58 and 65% of GPs did not use recommended BMI criterion to guide referrals
- and many GPs felt dissatisfied with the care they are able to give to patients with ED and feel inadequately trained in effective treatment strategies.

#### **4.3.4 Resource impact assessment**

No significant resource impact expected.

However, there may be additional GP time needed to carry out a physical and mental health review.

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<sup>15</sup> Currin L, Waller G, Treasure J, Nodder J, Stone C, Yeomans M. (2007) [The use of guidelines for dissemination of "best practice" in primary care of patients with eating disorders.](#)

## **4.4 Access and coordinated care**

### **4.4.1 Summary of suggestions**

#### **Improving access to services**

Stakeholders reported significant geographical variation in access and equal access to inpatient beds, with males having less access than females was also reported with treatment programmes and clinical settings often biased in favour of female orientated material.

#### **Coordination of care for people with an eating disorder**

Stakeholders highlighted the importance of coordinated care for people with an eating disorder as this may enable prompt identification, treatment and management (and potential comorbidities) before the person may require more resource intensive management.

Coordination of care and transition was reported as being varied in the UK. For example students with eating disorders who are transitioning between localities currently lack support during holiday periods. A stakeholder commented that increased support could prevent hospital admissions.

#### **Inpatient and day patient treatment**

A stakeholder highlighted the importance of improved communication by specialist eating disorders services or liaison psychiatry services. This could lead to reduced length of hospital stay and in turn could reduce both financial costs and improve the quality of life on both the person and their family or carers.

#### **Working with family members and carers**

Stakeholders highlighted the importance of involving patients, families and carers in care plans for young people and children. Processes need to be developed that support this greater level of involvement as role of carers in facilitating recovery is often crucial but that support is variable. Support for family members and carers can be increased by providing education and information resources.

### **4.4.2 Selected recommendations from development source**

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

**Table 7 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Improving access to services	<b>Improving access to services</b> NICE NG69 Recommendation 1.1.2
Coordination of care for people with an eating disorder	<b>Coordination of care for people with an eating disorder</b> NICE NG69 Recommendation 1.1.18
Inpatient and day patient treatment	<b>Inpatient and day patient treatment</b> NICE NG69 Recommendation 1.11.7
Working with family members and carers	<b>Working with family members and carers</b> NICE NG69 Recommendation 1.1.10

### **Improving access to services**

#### NICE NG69 – Recommendation 1.1.2

Ensure that all people with an eating disorder and their parents or carers (as appropriate) have equal access to treatments (including through self-referral) for eating disorders, regardless of:

- age
- gender or gender identity (including people who are transgender)
- sexual orientation
- socioeconomic status
- religion, belief, culture, family origin or ethnicity
- where they live and who they live with
- any physical or other mental health problems or disabilities.

### **Coordination of care for people with an eating disorder**

#### NICE NG69 – Recommendation 1.1.18

Take particular care to ensure services are well coordinated when:

- a young person moves from children's to adult services (see the NICE guideline on [transition from children's to adults' services](#))

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- more than one service is involved (such as inpatient and outpatient services, child and family services, or when a comorbidity is being treated by a separate service)
- people need care in different places at different times of the year (for example, university students).

### **Inpatient and day patient treatment**

#### NICE NG69 Recommendation 1.11.7

When a person is admitted to inpatient care for medical stabilisation, specialist eating disorder or liaison psychiatry services should:

- keep in contact with the inpatient team to advise on care and management, both during the admission and when planning discharge
- keep the person's family members or carers involved
- consider starting or continuing psychological treatments for the eating disorder.

### **Working with family members and carers**

#### NICE NG69 Recommendation 1.1.10

Be aware that the family members or carers of a person with an eating disorder may experience severe distress. Offer family members or carers assessments of their own needs as treatment progresses, including:

- what impact the eating disorder has on them and their mental health
- what support they need, including practical support and emergency plans if the person with the eating disorder is at high medical or psychiatric risk.

### **4.4.3 Current UK practice**

#### **Improving access to services**

The Children and Young People with an Eating Disorder (CYP ED) Waiting Times 2017 data<sup>16</sup> in England reports on access, and waiting times for NICE-approved

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<sup>16</sup> NHS England (2017) [Children and Young People with an Eating Disorder Waiting Times](#)

treatment following a routine or urgent referral for a suspected eating disorder. The main findings for Quarter 1 of 2017-2018 were:

- 73% of patients (206 out of 281) started urgent treatment within one week
- 79% of patients (1,067 out of 1,355) started routine treatment within four weeks
- the number of incomplete urgent pathways (patients waiting for urgent treatment) was 70. Of these 36 were waiting for more than one week.
- the number of incomplete routine pathways (patients waiting for routine treatment) was 529. Of these 231 were waiting for more than four weeks.

BEAT (2013)<sup>17</sup> also examined distance travelled for treatment for 471 respondents with eating disorders and concluded that 30% (143) had to travel more than 20 miles to access treatment, with 7% (33) having to travel more than 50 miles. Twenty-seven per cent (125) did not have transport access to the nearest treatment service.

BEAT (2015)<sup>18</sup> analysed the social, health and economic impact of eating disorders and concluded that there is significant variation in waiting times, referral pathways, service provision and treatment duration not only between regions but also by gender.

### **Coordination of care for people with an eating disorder**

Treasure et al (2005)<sup>19</sup> examined the coordination and transition of people with eating disorders between services. It was concluded that transition between service tiers can be problematic, particularly for adult services therefore effective collaboration and communication is paramount.

NHS England (2015)<sup>20</sup> also reported that there are no current collaborative systems between agencies such as education and local authorities. Poor communication with schools and colleges can result in inconsistent messages and management approaches.

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<sup>17</sup> BEAT (2013) [Waiting Times for treatment](#)

<sup>18</sup> BEAT (2015) [The costs of eating disorders- social, health and economic impacts](#)

<sup>19</sup> Treasure J, Schmidt U and Hugo P (2005) [Mind the gap: service transition and interface problems for patients with eating disorders](#)

<sup>20</sup> NHS England (2015) [Access and waiting time standard for children and young people with an eating disorder: commissioning guide](#)

### **Inpatient and day patient treatment**

The Joint Commissioning Panel for Mental Health (2013)<sup>21</sup> reported that patients with eating disorders need treatment episodes in non-specialist settings such as medical wards and general mental health units. Therefore liaison with other professionals is an important aspect of the specialist service on patient management and the facilitation of transfer to the eating disorder service when appropriate.

### **Working with family members and carers**

BEAT (2015)<sup>22</sup> examined the personal impact on the lives of people who have eating disorders and their carers and families. Over 90% of the survey respondents reported that this was a very significant or significant impact on their well-being and quality of life.

### **Resource impact assessment**

No significant resource impact expected.

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<sup>21</sup> Joint Commissioning Panel for Mental Health (2013) [Guidance for commissioners of eating disorder services](#)

<sup>22</sup> BEAT (2015) [The costs of eating disorders- social, health and economic impacts](#)

## **4.5 Additional areas**

### **Summary of suggestions**

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 20 September.

### **Access to specialist registered dietitian within community eating disorder teams for nutritional therapy**

A stakeholder suggested that all people with eating disorders have access to a specialist registered dietitian within community eating disorder multidisciplinary teams for nutritional assessment and therapy to support restoration and maintenance of a healthy body weight. There are no recommendations on this area within the development source NICE NG69.

### **Diabetes**

A stakeholder reported that eating disorders in people with Type 1 diabetes specifically can have significant associated excess mortality risk. There are 2 quality standards on diabetes in adults (QS6) and children and young people (QS125) which both published in 2016.

### **MARSIPAN regional hubs and networks**

A stakeholder supported the inclusion of MARSIPAN regional hubs and networks to ensure guidance on refeeding is implemented with best practice and professional support to non-specialist practitioners. There are no recommendations on this area within the development source NICE NG69.

### **Occupational therapy**

A stakeholder felt that this therapy is important to the care and treatment of people with eating disorders, particularly severe eating disorders. There are no recommendations on this area within the development source NICE NG69.

### **Psychological interventions with no current randomised controlled trials**

A stakeholder suggested considering a number of psychological interventions to include in this quality standard. These have no current Randomised Controlled Trials but have a developing evidence base such as Cognitive Analytic Therapy, Dialectical

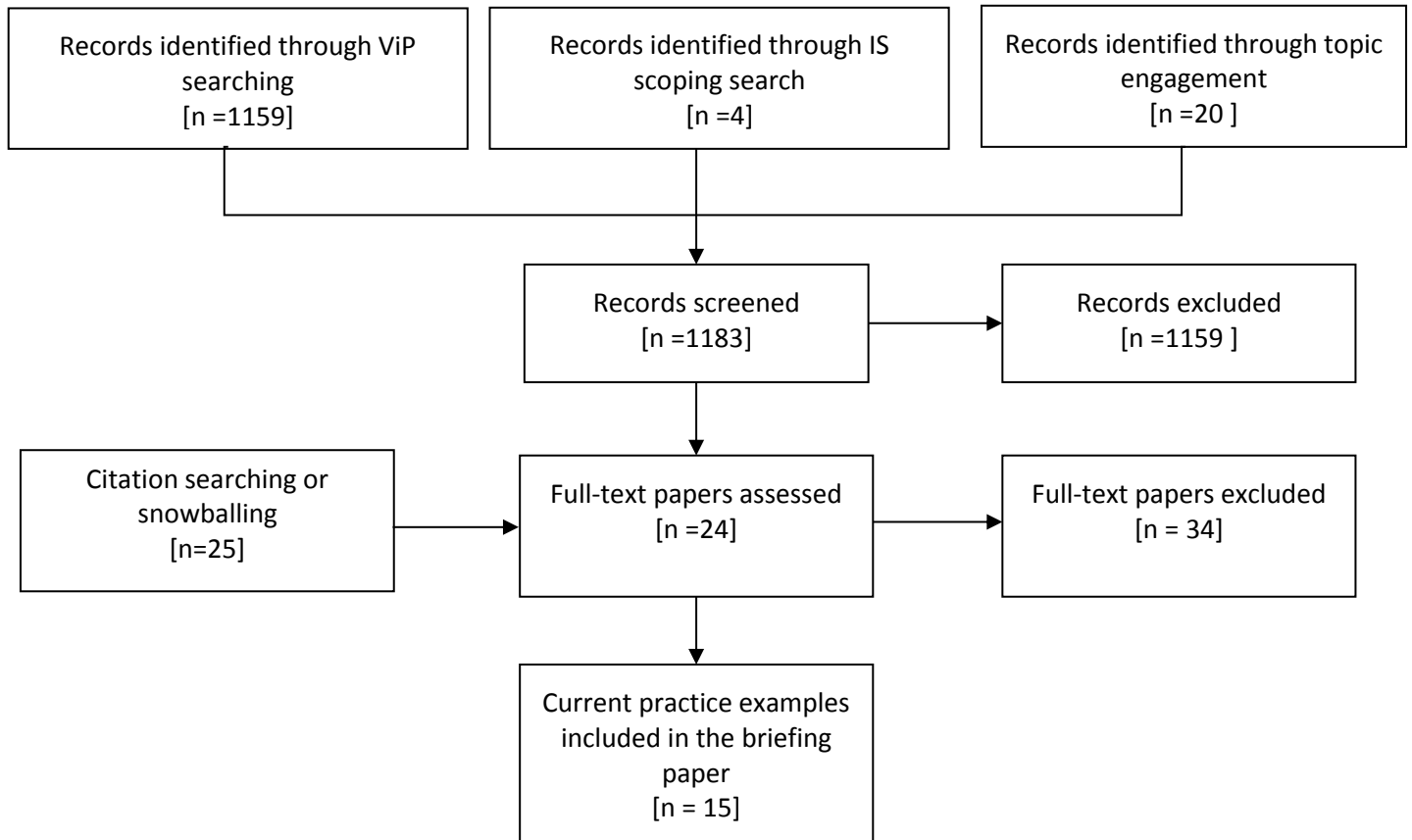
Behaviour Therapy and Compassion Focussed Therapy. It is not within the remit of NICE quality standards to reassess the evidence of a NICE guideline.

### **Training and competencies**

Stakeholders supported the need for training and monitoring with variation across the UK. Appropriate training (such as nasogastric tube placement and the four criteria method of x-ray interpretation) will ensure the delivery of a high standard of care and in turn increase the likelihood of recovery. The potential benefits of training include reduced patient harm, improved recognition of eating disorders through better sharing of information and better communication with the family and carers. Quality statements on staff training are not usually included in quality standards as healthcare professionals involved in assessing, caring for and treating people with eating disorders should have sufficient and appropriate training and competencies. Training may enable quality improvement to take place but is not considered as a quality improvement area.



### Appendix 1: Review flowchart



**Appendix 2: Suggestions from stakeholder engagement exercise**

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
<b>1. Identification and assessment</b>					
01	BEAT	Early intervention - Everyone who develops an eating disorder should receive rapid access to evidence-based treatment.	<p>Early intervention significantly increases the chance that treatment will be effective. Seeking help and being turned away or placed on a long waiting list is associated with reduced self-esteem, confidence in recovery, motivation and social isolation. Social isolation in particular is accepted as a significant predictor of poor outcome in people with mental health conditions.</p> <p>Receiving assessment and treatment at the earliest opportunity is recommended in the NICE guideline for eating disorders, including</p>	<p>NHS England have begun to publish waiting times statistics for the treatment of children and young people with an eating disorder and these appear to suggest significant improvement in recent years. However, little is known about the extent to which access to those services is being restricted. Beat Freedom of Information requests submitted in March 2017 found that 25 of the 44 Mental health trusts who responded did not at that time accept self-referrals.</p> <p>A Beat survey conducted in early 2017 about experiences of GP care, asked 1267 people whether the first GP they saw about their eating disorder ‘...emphasised the importance of getting help and treatment as soon as possible’. The split between those agreeing and</p>	<p>NHS Benchmarking conducts regular audits of services and it shortly to begin one for adult eating disorders services in England.</p> <p>NHS England ‘Experimental statistics’ on CYP eating disorders waiting times. Currently this data does not enable monitoring of waiting times at the service-level.</p> <p>In response to a recent NHS Digital consultation Beat requested that Version 3.0 of the Mental Health Services Data Set (MHSDS) should</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>recommendations 1.1.2, 1.2.1 and 1.2.6</p>	<p>disagreeing with the statement was close to 50:50. <a href="https://www.b-eat.co.uk/assets/000/001/177/EDAW_2017_summary_original.pdf">https://www.b-eat.co.uk/assets/000/001/177/EDAW_2017_summary_original.pdf</a></p> <p>One NHS Trust which provides an adult eating disorders service and responded to a Beat FOI explained that in addition to a minimum BMI threshold they also stipulated a minimum number of binge and purge episodes before someone with Bulimia would be able to access treatment at their service.</p> <p>In a BBC FOI conducted in 2016, 4 providers of Adult community based eating disorders services reported that they had a minimum BMI threshold in place.</p> <p>Some evidence about the wide variation across England and the rest of the UK, regarding access and waiting times is available from: <a href="http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf">http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf</a></p>	<p>include waiting times and data which would enable greater understanding of barriers to access for people of all ages referred to eating disorders treatment.</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				This source provides useful information on the importance of early intervention for children and young people with anorexia nervosa - <a href="http://bjp.rcpsych.org/content/199/1/5">http://bjp.rcpsych.org/content/199/1/5</a> .	
02	BDAMHSG	<p>Early identification/ intervention with timely access to effective stepped care pathways:</p> <p>Early identification and screening should be carried out in primary and secondary health care, social care, education and work settings where there is clinical concern considering the points noted in section 1.2.6 of NICE 2017 Guidelines and referrals made to an age appropriate MDT community based ED service for further</p>	<p>Delayed diagnosis/ intervention increases duration of illness, length of treatment, increased risks of mortality/ morbidity and poorer prognosis at significant cost to the individual, their family, healthcare, society and the wider UK economy (9) (2) all of which can be reduced through initiating early intervention. An early intervention model is appropriate for these disorders which requires prevention strategies alongside early identification/ intervention outside of specialist ED services (8). As EDs exist along a continuum treatment strategies should range from early interventions (guided self-help) to</p>	<p>Studies suggest that up to 50% of adults with (AN) and between 50% and 90% of adults with Bulimia Nervosa may not seek or receive treatment for their ED (9). EDs often exist without clinical detection and as such go unreported (3). Early identification and intervention is crucial as recovery is less likely if an ED has remained untreated for longer than 3-5 years (8). Studies associated a short interval between onset of symptoms and treatment intervention with good outcomes. There is considerable variation in the provision/ delivery ED service models nationally (4) with some areas in UK having no access to specialist ED services. Improved access to specialist treatment through funding and development of innovative service models delivered in primary/ secondary care, providing early intervention/</p>	<p>Early identification/ intervention with access to effective stepped care pathways is suggested to be of paramount importance to improve clinical outcome/ increase cost-effectiveness. Lack of access to appropriate treatment contributes to the severity/chronicity of the disorder, individual QOL, &amp; costs to the community/ health system (4, 8) A move towards earlier intervention for shorter periods is a focus as once weight loss is severe enough for medical intervention,</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		assessment/ intervention in a prompt and timely manner.	<p>intermediate interventions (group therapy/ advanced psychological therapy) and treatment approaches for complex presentations, all of which may be delivered across different treatment settings (9). When more transitional treatment options are available, treatment can also be individualized. Each patient can be directed to the most cost effective treatment that is also clinically appropriate. The result is improved outcomes at lower costs. Lack of access to appropriate treatment contributes to the severity and chronicity of the disorder, the impact on the individual, and the costs to the community and the health system. Effective liaison across different care structures/ organisations is pertinent due to the associated complexities of EDs. An integrated approach to the provision of services/ treatment is</p>	<p>intensive community treatment as an alternative/ step down from inpatients is recognised as an area requiring further evaluation (8). General practitioners are key primary health practitioners in shared treatment arrangements with dietitians and psychologists, concurrent with an early intervention and prevention focus at the community health service level and a stepped care approach contingent on illness severity. The latter involves less severe conditions being managed in the primary care setting, while specialist mental health services are the designated lead agencies in moderate to severe disorders; tertiary level specialist care focuses on the most severely ill (10) The challenge for clinicians and healthcare services is to provide consistency, continuity and quality of care for ED patients, given their inherent difficulties in engaging with health services and their potential ‘slippage’ into potential gaps in the transition of care across services.</p>	<p>treatment may be less effective entails greater risks, and poorer prognosis than when intervention is provided earlier. Commissioning for the treatment of patients with lower severity ED, using a stepped care model, would reduce morbidity and the overall cost of ED to health service (8). The Royal College Psychiatrist (2012) suggest ideas for service model should be developed in collaboration with primary and secondary care and tested in terms of their efficacy. The JCPMH 2013 propose a series of treatment settings are required along a continuum offering a range of treatment intensities within primary,</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			fundamental to the delivery of high-quality/ safe and effective care.		secondary and tertiary care. Tier 1, 2 or 3 services offer early intervention and intermediate level treatment in the community providing a gatekeeping role to Tier 4 services.
03	SCM4	People with an eating disorder should receive treatment at the earliest opportunity	<p>There is good evidence that early intervention is linked with improved outcome.</p> <p>Early intervention is recommended by NICE</p>		Early intervention
04	SCM 3	Early intervention and reduced waiting times	<p>Early intervention may reduce the need for more intensive treatments in the future as early intervention may stop patients deteriorating.</p> <p>More emphasis on this may help</p>	Currently very long waiting lists for some services, which can result in patients getting more unwell.	Early intervention

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			commission more community services.		
05	SCM5	Ensuring that services are not offering or withholding treatments based on Body Mass Index (BMI).	Patients are rejected for having a BMI that is too high or too low to access services.	This happens a lot currently despite NICE guidance 2017 being clear that this should not happen. Patients get the message that they need to “lose weight” to become more unwell, to gain access to any treatment. Or are left in crisis at very low weight in the community with only GP support because the local ED team say they will not offer treatment because BMI is too low.	
06	BDAMHSG	Early identification/ intervention with timely access to effective stepped care pathways: Early identification and screening should be carried out in primary and secondary health care, social care, education and	Delayed diagnosis/ intervention increases duration of illness, length of treatment, increased risks of mortality/ morbidity and poorer prognosis at significant cost to the individual, their family, healthcare, society and the wider UK economy (9) (2) all of which can be reduced through initiating early intervention.	Studies suggest that up to 50% of adults with (AN) and between 50% and 90% of adults with Bulimia Nervosa may not seek or receive treatment for their ED (9). EDs often exist without clinical detection and as such go unreported (3). Early identification and intervention is crucial as recovery is less likely if an ED has remained untreated for longer than 3-5 years (8). Studies associated a short interval	Early identification/ intervention with access to effective stepped care pathways is suggested to be of paramount importance to improve clinical outcome/ increase cost-effectiveness. Lack of access to appropriate treatment contributes to the

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		<p>work settings where there is clinical concern considering the points noted in section 1.2.6 of NICE 2017 Guidelines and referrals made to an age appropriate MDT community based ED service for further assessment/ intervention in a prompt and timely manner.</p>	<p>An early intervention model is appropriate for these disorders which requires prevention strategies alongside early identification/ intervention outside of specialist ED services (8). As EDs exist along a continuum treatment strategies should range from early interventions (guided self-help) to intermediate interventions (group therapy/ advanced psychological therapy) and treatment approaches for complex presentations, all of which may be delivered across different treatment settings (9). When more transitional treatment options are available, treatment can also be individualized. Each patient can be directed to the most cost effective treatment that is also clinically appropriate. The result is improved outcomes at lower costs. Lack of access to appropriate treatment contributes to the severity</p>	<p>between onset of symptoms and treatment intervention with good outcomes. There is considerable variation in the provision/ delivery ED service models nationally (4) with some areas in UK having no access to specialist ED services. Improved access to specialist treatment through funding and development of innovative service models delivered in primary/ secondary care, providing early intervention/ intensive community treatment as an alternative/ step down from inpatients is recognised as an area requiring further evaluation (8). General practitioners are key primary health practitioners in shared treatment arrangements with dietitians and psychologists, concurrent with an early intervention and prevention focus at the community health service level and a stepped care approach contingent on illness severity. The latter involves less severe conditions being managed in the primary care setting, while specialist mental health services are the designated lead agencies in moderate to severe disorders; tertiary level specialist care focuses</p>	<p>severity/chronicity of the disorder, individual QOL, &amp; costs to the community/ health system (4, 8) A move towards earlier intervention for shorter periods is a focus as once weight loss is severe enough for medical intervention, treatment may be less effective entails greater risks, and poorer prognosis than when intervention is provided earlier. Commissioning for the treatment of patients with lower severity ED, using a stepped care model, would reduce morbidity and the overall cost of ED to health service (8). The Royal College Psychiatrist (2012) suggest ideas for service model should be developed in</p>



ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>and chronicity of the disorder, the impact on the individual, and the costs to the community and the health system. Effective liaison across different care structures/ organisations is pertinent due to the associated complexities of EDs. An integrated approach to the provision of services/ treatment is fundamental to the delivery of high-quality/ safe and effective care.</p>	<p>on the most severely ill (10) The challenge for clinicians and healthcare services is to provide consistency, continuity and quality of care for ED patients, given their inherent difficulties in engaging with health services and their potential 'slippage' into potential gaps in the transition of care across services.</p>	<p>collaboration with primary and secondary care and tested in terms of their efficacy. The JCPMH 2013 propose a series of treatment settings are required along a continuum offering a range of treatment intensities within primary, secondary and tertiary care. Tier 1, 2 or 3 services offer early intervention and intermediate level treatment in the community providing a gatekeeping role to Tier 4 services.</p>
07	SCM6	Risk assessment in primary care	There is good evidence that early access to specialist care improves outcome	Primary care remains the main gateway for access to specialist care, the need and urgency for which depends on risk assessment. Yet evidence suggest highly variable skills and	There have been audits (e.g. South London audit – can't find it on line but it was led by Ulrike Schmidt) and reports ( <a href="https://www.beat.co.uk/about-beat/media-centre/press-releases/8428-3-out-of-10-eating-disorder-">https://www.beat.co.uk/about-beat/media-centre/press-releases/8428-3-out-of-10-eating-disorder-</a>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>knowledge within primary care in identifying eating disorders and assessing risk</p>	<p>sufferers-not-referred-for-treatment) looking at the question of GP assessment and triage.</p> <p>The main data source would be a comparison of GP incidence and prevalence with population level prevalence but eating disorders were excluded from the last psychiatric morbidity survey for reasons that are unclear.</p>
08	SCM 6	<p>Access to empirically supported psychological interventions in adult services</p>	<p>Early treatment response with evidence based interventions is the best predictor of outcome</p>	<p>Children and young people’s access to care is currently undergoing radical transformation, but this is not matched in adult services where waiting lists are the norm and patients report having to get more unwell to be prioritised for care</p>	<p>Mental health services dataset and RTT data should provide the necessary figures but it is not currently possible to pull out patients by diagnosis, and ED is not a separate pathway within adult community care.</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
09	SCM 6	Identification of binge eating disorder among high risk populations	Binge eating disorder is underrepresented in help seeking populations compared to the expected population prevalence.	Binge eating disorder is present around 2% of the general population and up to 20% in obese populations. Awareness, diagnosis, and treatment of binge-eating disorder (BED) is poor. Left untreated, BED causes significant impairment, reduced quality of life, and decreased productivity. Whilst treatments for BED do not reduce weight, they may halt weight gain, and thus has the potential to reduce long term morbidity. Early recognition and accurate diagnosis may help mitigate the long-term impact of BED.	Unlikely to be identified in primary care. HES data likely to be poor on BED in community services. MHSDS may improve this depending on adherence to data collection.
10	SCM 6	Access to appropriate specialist medical care	Patients with ED have medical (psychiatry and physician/paediatric) needs	Medical needs of patients with ED include acute medical monitoring, access to specialist psychopharmacological interventions as well as monitoring of physical impact of ED such as growth and development (young people) and bone density (all ages).	Recommendations on staffing for ED services from specialist reports e.g. <a href="http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf">http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf</a> , <a href="https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guid.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/07/cyp-eating-disorders-access-waiting-time-standard-comm-guid.pdf</a> comparison with workforce data.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
<b>2. Treating eating disorders</b>					
11	BEAT	Multidisciplinary approach to treatment	A multidisciplinary approach to treatment is important given the complexity of eating disorders. It is advocated in recommendations 1.12.3, 1.1.15 and 1.3.1.	<p>Access to treatment delivered in a multidisciplinary way (including through teams which can benefit from the input of dietetics and psychiatry) is highly variable across England and the UK.</p> <p>Evidence about gaps in the specialist eating disorders workforce can be found here - <a href="http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf">http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf</a>.</p>	<p>Health Education England has recently published a Workforce strategy. This included an ambition to recruit an additional 30 Consultant psychiatrists for Children and young people’s eating disorders services. We expect that HEE will publish updates on progress against this.</p> <p>The HEE workforce strategy has tasked STPs with developing local workforce plans. Some of these plans may provide data at the local level on the skill mix of eating disorders services.</p>

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					<p>The Access and waiting times for Children and young people with an eating disorder specified an indicative workforce mix which would be suitable for a CEDS-CYP service and a tool to enable commissioners and providers to calculate the staff required to meet local need. These specifications could be contrasted with the staff employed at CEDS-CYP services.</p>
12	SCM 3	<p>Stronger emphasis on achieving weight gain as part of interventions in anorexia</p>	<p>There's limited and mixed evidence for which specific intervention has the best outcome but the overall consensus is that weight gain is the most important target for recovery.</p> <p>NICE recommend:</p>	<p>There is currently lots of variation in the amount of weight gain that is achieved and expected as part of different interventions in anorexia nervosa, despite it being a crucial component of recovery.</p>	<p>Achieving weight gain</p>

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			<p>When treating anorexia nervosa, be aware that:</p> <ul style="list-style-type: none"> <li>• helping people to reach a healthy body weight or BMI for their age is a key goal and</li> <li>• weight gain is key in supporting other psychological, physical and quality of life changes that are needed for improvement or recovery.</li> </ul>		
13	SCM5	Establishment of community MDT eating disorders teams in all areas of the country.	As Inpatients should only be used for medical stabilisation ( NICE 2017), this means that community teams are required to deliver the treatments for most cases. An MDT approach is needed for Anorexia Nervosa	At the moment there are area that have no ED service. In other areas community teams are only a nurse, but no access to Dietetics, Psychology etc.	
14	BDAMHSG	Prompt physical health assessment and improved	Robust evidence shows that mental health cannot be reached without	Clinical expertise and assessment skills remains a critical component of ED treatment given that	Research shows that the sooner ED behaviours are

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		<p>access to registered dietitian within community eating disorder teams for nutritional therapy.</p> <p>All Eating Disorder (ED) patients, including children and young people to have a prompt physical health assessment and access to a specialist Registered Dietitian (RD) within ED Multidisciplinary Team (MDT) for nutritional assessment of growth and energy requirements and nutritional therapy to support restoration / maintenance of a healthy body weight/ Body Mass Index (BMI).</p>	<p>recovery of weight. A key therapeutic goal in AN is to restore body weight, and thereby mitigate brain anomalies and important somatic, psychological and cognitive complications involved in the disorder, and many symptoms resolve with increased weight (1). Associated morbidity &amp; mortality, arises in part from malnutrition/ compensatory behaviours due to medical complications such as cardiac arrest and electrolyte imbalance. BMI &lt; 18.5 kg/m<sup>2</sup> increases the risk for irregular menstruation, infertility females, anaemia and immunodeficiency The longer a person remains in a state of suboptimal nutrition or continues with ED behaviours, the more persistent and severe the disorder can become, with poorer prognosis. Medical management and nutritional rehabilitation including core goals of</p>	<p>several questions and concerns remain inadequately addressed by the existing research literature.</p> <p>(4) suggests 1.2 Whole Time Equivalent RD per 1 million population. (4) survey into ED service provision nationally reported 82% of services utilised nutrition advice and monitoring as a main therapeutic approach in AN, 54% in Binge Eating Disorder and 62% for ED not otherwise Specified, yet only 54% of services responding in the survey had access to a RD within the MDT. Currently, there is no consistent approach and a paucity of evidence to support best practice for weight restoration/ nutritional management in this patient group. (5).</p>	<p>stopped and nutrition and physical health restored the better the prognosis and the better a person responds to psychotherapy. Evidence that discharge at a low weight is associated with a poorer outcome and a higher readmission rate (6). A low BMI at the beginning of treatment has been identified as one of the most important risk factors for poor prognosis in AN. Extremes of BMI in adults with ED is associated with poorer quality of life (1). Weight restoration to a healthy BMI range and the maintenance after intensive treatment demonstrate important prognostic factors. Approaching or achieving normal weight/ nutritional</p>

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			<p>healthy weight restoration and adequate nutritional status, return of menses for women and reduction in dietary restraint, and normalization of eating patterns and behaviours are primary treatment goals in Anorexia Nervosa (AN) (2). RD's assess, educate and counsels patients/ parents/ carers and staff on food/ nutrition issues they are able to provide nutritional guidelines to promote growth and development, and meet nutritional needs through design, implementation and managing safe and effective nutritional strategies that enhance growth, development and recovery from disordered eating and promote lifelong health.</p> <p>Assessing appropriate treatment/ settings depends on the assessment of both physical and psychological risk and the patient's wishes. The</p>		<p>status during treatment indicates a better outcome (3). International Guidelines (2, 3) and a review of the available literature suggest treatment strategies for EDs include: health and weight restoration through medical and nutritional therapy, psycho-education about health, nutrition, and the effects of the disorder delivered either in groups or individually; Medical management and nutritional rehabilitation includes; correcting nutritional deficit's in someone in a starved state and preventing complications of re-feeding syndrome; restoration of weight and nutritional status; rehydration and correction of serum</p>



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			<p>medical needs of the individual determine the treatment site, most importantly the physical parameters of nutritional status, weight/ loss and cardiac and metabolic status (2, 3)</p>		<p>electrolytes. Ideally this should include input from a consultant physician with a special interest in nutrition alongside an experienced dietitian within a specialist EDs team (NICE) delivered in combination with psychotherapeutic approaches (3). Nutrition intervention alongside other psychological therapies is recommended as many of the symptoms assumed to be a sign of psychiatric co-morbidity may result from symptoms of starvation and there is insufficient evidence to support any of the psychotherapies alone as having an impact on weight change in people with EDs (3, 4, 7) (8).</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
15	BEAT	Multidisciplinary approach to treatment	A multidisciplinary approach to treatment is important given the complexity of eating disorders. It is advocated in recommendations 1.12.3, 1.1.15 and 1.3.1.	<p>Access to treatment delivered in a multidisciplinary way (including through teams which can benefit from the input of dietetics and psychiatry) is highly variable across England and the UK.</p> <p>Evidence about gaps in the specialist eating disorders workforce can be found here - <a href="http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf">http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf</a>.</p>	<p>Health Education England has recently published a Workforce strategy. This included an ambition to recruit an additional 30 Consultant psychiatrists for Children and young people’s eating disorders services. We expect that HEE will publish updates on progress against this.</p> <p>The HEE workforce strategy has tasked STPs with developing local workforce plans. Some of these plans may provide data at the local level on the skill mix of eating disorders services.</p> <p>The Access and waiting times for Children and young people with an eating</p>

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					disorder specified an indicative workforce mix which would be suitable for a CEDS-CYP service and a tool to enable commissioners and providers to calculate the staff required to meet local need. These specifications could be contrasted with the staff employed at CEDS-CYP services.
16	SCM 2	The use of Specialist Supportive Clinical Management (SSCM) in the treatment of children, young people and adults with Eating Disorders, establishing a clear pathway for its use by a range of Eating Disorders health professionals	The core elements of SSCM are that it is flexible, not structured and tailored to an individual patient, relying on the development of a strong therapeutic relationship to support an individual to make changes. It is one of the recommendations for treatment under the current guidelines.	Training for nurses and AHPs in this area is not the equivalent to Psychology or Psychotherapy. Therefore standardisation of the core elements of SCM may be needed	

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17	SCM 1	The delivery of outpatient guided self-help to adults with bulimia nervosa, binge eating disorder and allied states.	In most cases this should be the first step (in a stepped care treatment strategy) as indicated in the new NICE guidance.	The outpatient treatment of people with eating disorders is very variable. In my 30 years of experience providing training across the NHS, few staff have received the necessary training, treatments are not delivered following evidence-based protocols, and there is little or no supervision.	There are none.
18	SCM 1	The delivery of outpatient guided self-help to adults with bulimia nervosa, binge eating disorder and allied states.	In most cases this should be the first step (in a stepped care treatment strategy) as indicated in the new NICE guidance.	The outpatient treatment of people with eating disorders is very variable. In my 30 years of experience providing training across the NHS, few staff have received the necessary training, treatments are not delivered following evidence-based protocols, and there is little or no supervision.	There are none.
19	AFTSP	There is evidence that systemic and family therapies can enhance effectiveness of treatment of young people with	The following might be helpful: Couturier J, Kimber M, & Szatmari P. (2013) Efficacy of family-based treatment for adolescents with eating disorders: a systematic review		

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		<p>eating disorders above the effectiveness of individual therapy. Availability and resourcing of family therapists may vary across geographical areas.</p> <p>Availability of and access of families to systemic and family therapies could be an important quality improvement focus.</p>	<p>and meta-analysis. International Journal of Eating Disorders, 46(1), pp. 3-11. doi: 10.1002/eat.22042.</p> <p>Downs, K.J. and Blow, A.J. (2011) A substantive and methodological review of family-based treatment for eating disorders: The last 25 years of research, Journal of Family Therapy, 35, pp. 3–28. doi: 10.1111/j.1467-6427.2011.00566.x.</p> <p>Gelin, Z., Fuso, S., Hendrick, S., Cook-Darzens, S. and Simon, Y. (2014) The effects of a multiple family therapy on adolescents with eating disorders: An outcome study, Family Process, 54(1), pp. 160–172. doi: 10.1111/famp.12103</p>		
20	SCM 1	The delivery of outpatient family-based treatment to young people with anorexia nervosa or bulimia nervosa	This is the clear treatment of choice as indicated in the new NICE guidance.	The outpatient treatment of people with eating disorders is very variable. In my 30 years of experience providing training across the NHS, few staff have received the necessary training, treatments are not delivered following	There are none.

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				evidence-based protocols, and there is little or no supervision.	
21	SCM 1	The delivery of eating disorder focused outpatient cognitive behaviour therapy (CBT-ED) to adults with bulimia nervosa, binge eating disorder and atypical eating disorders, and young people with equivalent states.	This is the clear treatment of choice as indicated in the new NICE guidance.	The outpatient treatment of people with eating disorders is very variable. In my 30 years of experience providing training across the NHS, few staff have received the necessary training, treatments are not delivered following evidence-based protocols, and there is little or no supervision.	There are none.
22	TEWSNHSFT	Engagement of patients with eating disorders in their care and treatment.	Level of engagement of patients with moderate to severe eating disorders is crucial for helping patients progress towards improvement and recovery.	Levels of engagement, and interventions focussed around engagement vary across providers. Engagement was considered outside the scope of NICE.	<ul style="list-style-type: none"> <li>• Examination of the literature on interventions that report on and support engagement, e.g. clinical evaluation of Cognitive Analytic Therapy that reported good levels of</li> </ul>

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					engagement, but was outside the scope of NICE.
23	SCM 1	The delivery of eating disorder focused outpatient cognitive behaviour therapy (CBT-ED) to adults with bulimia nervosa, binge eating disorder and atypical eating disorders, and young people with equivalent states.	This is the clear treatment of choice as indicated in the new NICE guidance.	The outpatient treatment of people with eating disorders is very variable. In my 30 years of experience providing training across the NHS, few staff have received the necessary training, treatments are not delivered following evidence-based protocols, and there is little or no supervision.	There are none.
24	AFTSP	There is evidence that systemic and family therapies can enhance effectiveness of treatment of young people with eating disorders above the effectiveness of individual therapy. Availability and	The following might be helpful: Couturier J, Kimber M, & Szatmari P. (2013) Efficacy of family-based treatment for adolescents with eating disorders: a systematic review and meta-analysis. International Journal of Eating Disorders, 46(1), pp. 3-11. doi: 10.1002/eat.22042.		

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		<p>resourcing of family therapists may vary across geographical areas. Availability of and access of families to systemic and family therapies could be an important quality improvement focus.</p>	<p>Downs, K.J. and Blow, A.J. (2011) A substantive and methodological review of family-based treatment for eating disorders: The last 25 years of research, <i>Journal of Family Therapy</i>, 35, pp. 3–28. doi: 10.1111/j.1467-6427.2011.00566.x. Gelin, Z., Fuso, S., Hendrick, S., Cook-Darzens, S. and Simon, Y. (2014) The effects of a multiple family therapy on adolescents with eating disorders: An outcome study, <i>Family Process</i>, 54(1), pp. 160–172. doi: 10.1111/famp.12103</p>		
25	AFTSP	<p>There is evidence that systemic and family therapies can enhance effectiveness of treatment of young people with eating disorders above the effectiveness of individual therapy. Availability and</p>	<p>The following might be helpful: Couturier J, Kimber M, &amp; Szatmari P. (2013) Efficacy of family-based treatment for adolescents with eating disorders: a systematic review and meta-analysis. <i>International Journal of Eating Disorders</i>, 46(1), pp. 3-11. doi: 10.1002/eat.22042.</p>		



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		<p>resourcing of family therapists may vary across geographical areas. Availability of and access of families to systemic and family therapies could be an important quality improvement focus.</p>	<p>Downs, K.J. and Blow, A.J. (2011) A substantive and methodological review of family-based treatment for eating disorders: The last 25 years of research, <i>Journal of Family Therapy</i>, 35, pp. 3–28. doi: 10.1111/j.1467-6427.2011.00566.x. Gelin, Z., Fuso, S., Hendrick, S., Cook-Darzens, S. and Simon, Y. (2014) The effects of a multiple family therapy on adolescents with eating disorders: An outcome study, <i>Family Process</i>, 54(1), pp. 160–172. doi: 10.1111/famp.12103</p>		
<p><b>3. Physical health assessment and monitoring for all eating disorders</b></p>					
26	SCM 2	Physical health monitoring and management of medical co-morbidities in the community setting	Given the high mortality rate of Eating Disorders, and that the majority of patients are treated in the community, it is important to ensure the quality and effectiveness	Ensuring guidance on Physical Health management is included in all assessment documentation. The wider use of Shared Care protocols with Primary Care	

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			of monitoring and managing the physical health and co-morbidities of individuals.		
27	SCM4	People with an eating disorder should have their progress in treatment monitored regularly	<p>Monitoring of treatment progress helps to ensure that patients are in the most appropriate treatment for their condition. It also allows for benchmarking of clinical effectiveness.</p> <p>Use of standardised outcomes measures is recommended by NICE.</p>	<p>There is likely to be wide variability across services regarding outcome monitoring.</p> <p>Improved monitoring of progress would ensure that patients who are not responding to treatment are identified and treatment packages amended accordingly. Supports more effective use of resources and identifies training needs.</p>	<p>Monitoring treatment</p> <p>Use of outcome measures</p>
28	SCM 2	Physical health monitoring and management of medical co-morbidities in the community setting	Given the high mortality rate of Eating Disorders, and that the majority of patients are treated in the community, it is important to ensure the quality and effectiveness of monitoring and managing the	Ensuring guidance on Physical Health management is included in all assessment documentation. The wider use of Shared Care protocols with Primary Care	

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			physical health and co-morbidities of individuals.		
29	SCM 2	Physical health monitoring and management of medical co-morbidities in the community setting	Given the high mortality rate of Eating Disorders, and that the majority of patients are treated in the community, it is important to ensure the quality and effectiveness of monitoring and managing the physical health and co-morbidities of individuals.	Ensuring guidance on Physical Health management is included in all assessment documentation. The wider use of Shared Care protocols with Primary Care	
30	BDAMHSG	Improved Support and ongoing safe community management of SEAD patients: Yearly review by GP, continued support offered from community team to ensure weight stabilisation at a medically safe weight to prevent hospital	For some patients with a long history of AN, the best option may be to maintain a weight safe enough to allow some quality of life and prevent hospital admission. This normally requires a BMI of at least 15 kg/m <sup>2</sup> (18).  Treatment goals for ED patients are not always based on full recovery	Achievement of these goals varies by treatment intervention, settings and the patients stage of illness, and progress with nutritional and psycho-therapies (2). Current treatment pathways vary by disorder type, in relation to treatment goals, interventions, settings and approaches, dependent on the nature of patient's symptoms, medical condition, treatment history, motivation toward treatment, as well as logistic considerations. As	In patients with severe and enduring AN who may not be able to recover from their ED, nutritional treatment may have more modest goals and may focus on personalised recovery, maintaining a safe and stable weight and improving quality

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		admissions and allow quality of life.	and remission of all symptoms but instead for more chronic patients may reflect improvements in social and occupational function, allowing patients to have a more positive focus on improving their quality of life instead of focusing solely on their weight (9).	such it is recognised that no single approach is effective for every person (19), and a comprehensive individual assessment is required to consider the several dimensions of need in order to provide an appropriate treatment plan which provides treatment along a continuum of intensity and support (19) for individual patient needs.	of life rather than aiming for an optimal weight (3, 4) (8)
31	TEWSNHSFT	Patient choice in therapeutic interventions for eating disorders.	Patients should be allowed a degree of choice regarding second-line interventions that include psychological therapies with an emerging evidence base. E.g. Cognitive Analytic Therapy, Dialectical Behaviour Therapy, Compassion Focussed Therapy.	NICE has recommended a narrow range of psychological interventions for people suffering from eating disorders. The evidence base for these interventions excludes patient engagement, people with BMI below 15, males, and people suffering co-morbid conditions. Many patients have tried at least one of the recommended treatments and found themselves unable to progress (e.g., Cognitive Behaviour Therapy for Eating Disorders).	<ul style="list-style-type: none"> <li>• NICE 2017 NG69: Eating disorders: recognition and treatment.</li> <li>• Clinical literature on Cognitive Analytic Therapy, Compassion Focussed Therapy, Dialectical Behaviour Therapy.</li> </ul>

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32	SCM5	Ensuring the yearly GP check with patients with Anorexia Nervosa ( NICE 2017),	to follow up patients that maybe very low weight, or relapsing, but avoiding contact with services.	Patients not responding to GP recall should be followed up to ensure they are not in crisis and avoiding contact. This should help prevent avoidable harm to patients, who slip through the net, and end up in A and E, or with a lengthy hospital stay because they have become so unwell.	
33	BDAMHSG	<p>Prompt physical health assessment and improved access to registered dietitian within community eating disorder teams for nutritional therapy.</p> <p>All Eating Disorder (ED) patients, including children and young people to have a prompt physical health assessment and access to a</p>	<p>Robust evidence shows that mental health cannot be reached without recovery of weight. A key therapeutic goal in AN is to restore body weight, and thereby mitigate brain anomalies and important somatic, psychological and cognitive complications involved in the disorder, and many symptoms resolve with increased weight (1). Associated morbidity &amp; mortality, arises in part from malnutrition/</p>	<p>Clinical expertise and assessment skills remains a critical component of ED treatment given that several questions and concerns remain inadequately addressed by the existing research literature.</p> <p>(4) suggests 1.2 Whole Time Equivalent RD per 1 million population. (4) survey into ED service provision nationally reported 82% of services utilised nutrition advice and monitoring as a main therapeutic approach in AN, 54% in Binge Eating Disorder and 62% for ED not otherwise Specified, yet only 54% of services responding in</p>	<p>Research shows that the sooner ED behaviours are stopped and nutrition and physical health restored the better the prognosis and the better a person responds to psychotherapy. Evidence that discharge at a low weight is associated with a poorer outcome and a higher readmission rate (6). A low BMI at the beginning of</p>

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		<p>specialist Registered Dietitian (RD) within ED Multidisciplinary Team (MDT) for nutritional assessment of growth and energy requirements and nutritional therapy to support restoration / maintenance of a healthy body weight/ Body Mass Index (BMI).</p>	<p>compensatory behaviours due to medical complications such as cardiac arrest and electrolyte imbalance. BMI &lt; 18.5 kg/m<sup>2</sup> increases the risk for irregular menstruation, infertility females, anaemia and immunodeficiency The longer a person remains in a state of suboptimal nutrition or continues with ED behaviours, the more persistent and severe the disorder can become, with poorer prognosis. Medical management and nutritional rehabilitation including core goals of healthy weight restoration and adequate nutritional status, return of menses for women and reduction in dietary restraint, and normalization of eating patterns and behaviours are primary treatment goals in Anorexia Nervosa (AN) (2). RD's assess, educate and counsels patients/ parents/ carers and staff on food/ nutrition issues they are</p>	<p>the survey had access to a RD within the MDT. Currently, there is no consistent approach and a paucity of evidence to support best practice for weight restoration/ nutritional management in this patient group. (5).</p>	<p>treatment has been identified as one of the most important risk factors for poor prognosis in AN. Extremes of BMI in adults with ED is associated with poorer quality of life (1). Weight restoration to a healthy BMI range and the maintenance after intensive treatment demonstrate important prognostic factors. Approaching or achieving normal weight/ nutritional status during treatment indicates a better outcome (3). International Guidelines (2, 3) and a review of the available literature suggest treatment strategies for EDs include: health and weight restoration through medical and nutritional therapy, psycho-education about</p>

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			<p>able to provide nutritional guidelines to promote growth and development, and meet nutritional needs through design, implementation and managing safe and effective nutritional strategies that enhance growth, development and recovery from disordered eating and promote lifelong health.</p> <p>Assessing appropriate treatment/ settings depends on the assessment of both physical and psychological risk and the patient's wishes. The medical needs of the individual determine the treatment site, most importantly the physical parameters of nutritional status, weight/ loss and cardiac and metabolic status (2, 3)</p>		<p>health, nutrition, and the effects of the disorder delivered either in groups or individually; Medical management and nutritional rehabilitation includes; correcting nutritional deficit's in someone in a starved state and preventing complications of re-feeding syndrome; restoration of weight and nutritional status; rehydration and correction of serum electrolytes. Ideally this should include input from a consultant physician with a special interest in nutrition alongside an experienced dietitian within a specialist EDs team (NICE) delivered in combination with psychotherapeutic approaches (3). Nutrition</p>

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					intervention alongside other psychological therapies is recommended as many of the symptoms assumed to be a sign of psychiatric co-morbidity may result from symptoms of starvation and there is insufficient evidence to support any of the psychotherapies alone as having an impact on weight change in people with EDs (3, 4, 7) (8).
<b>4. Access and coordinated care</b>					
34	SCM 2	Reducing waiting times and improving access to services for young people.	Ensuring that services adhere to the Access and Waiting Time standards	Extending the use of innovative initiatives such as Transition Clinics (currently being piloted in Sheffield)	



ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
35	BDAMHSG	<p>Community treatment close to home and continuity of care across treatment settings:</p> <p>All ED patients who are medically and psychologically stable should be seen in a community ED MDT service close to home where appropriate Inpatient settings to be reserved for those with acute physical/psychologically risks and utilised for a brief period of medical/ psychological stabilisation with prompt discharge back to the community ED service for continued treatment when</p>	<p>In AN inpatient regimes are widely used, yet often their acceptability is limited with outpatient care preferred due to its perceived advantages in avoiding loss of usual social contacts and interruption to work/ education. The benefits of inpatient weight restoration and the assumption that hospital is the best venue for refeeding once medical stability has been achieved remain unsupported by current evidence (11) and its advantage where patients may be 'safely' cared for as an outpatient is unproven. ED treatment needs to progress from a traditional dichotomous approach of inpatient and outpatient treatment towards a continuum of care model offering varying levels of community treatment (outpatient, day patient, assertive outreach, group programmes(12).</p>	<p>The incidences of AN diagnosed and entering inpatient treatment in England has continued to rise on average 7% year on year since 2009 (9). The duration of hospital stays increased by more than 4 weeks during the past decade in the UK(4). (15) Inpatient treatment programmes for adults with AN have been associated with poor treatment outcomes, including continued ED psychopathology following discharge and hospital readmissions. The lack of high-quality evidence for the efficacy of inpatient intervention for AN has raised uncertainty about the suitability of inpatient settings for the treatment of AN, particularly longer term treatment programmes aimed at health behaviour change. There is limited evidence to guide the most appropriate treatment setting with few studies comparing different settings in ED's with inconclusive findings for a more advantageous treatment setting. No specific national standards for ED community services guiding service provision. As such interpretation of (3), (16) and the Quality Eating Disorder</p>	<p>NICE 2004, 2017 recommend that patients with EDs should be treated within a community ed service close to their home, with more intensive care of a hospital admission mandatory where there is high medical or psychiatric risk. Recommending inpatient treatment to be considered as a last resort used in only a minority of cases of acute or psychiatric need for a short intervention as it is expensive and time consuming and there is limited evidence for its effectiveness over community treatment. There is insufficient evidence to determine any advantage</p>

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		<p>risk reduction has been achieved.</p>	<p>Unfortunately these developments have not necessarily transferred into clinical practice, or resulted in improved care and service provision nationwide as it continues to be recognised that access to high quality specialist community care remains variable (4). Community ED services including Day service programmes (DSP) are increasingly common, offering early intervention as well as intensive treatment for more severe patients, allowing step up/down based on individual needs (13). Emerging evidence suggests DSP's could offer a cheaper approach, with similar clinical benefits to inpatient treatment (14). Continuity of care between treatment settings and services is essential when working with ED patients with complex presentations</p>	<p>inpatient Standards(17) has resulted in considerable variation in community service models nationwide (14). The current service settings available for ED treatment include GP care, Community Mental Health Team, specialist ED Community outpatient, intensive outpatient, day service and inpatient (8), however this is not reflective of the services delivered nationwide and access to services is not equitable for patients nationwide and no controlled studies have pointed out which treatment model or setting is most effective for adult/ adolescent patients. (4). The cost of inpatient treatment is high. Community Specialist MDT ED treatment provide reasonable alternatives for many patients, yet are not widely available, and the evidence for their effectiveness is based on observational, naturalistic studies rather than Randomised Control Trials' limiting their validity.</p>	<p>for inpatient care over outpatient psychological treatments for patients who are not so severely ill as to need emergency treatment (NICE 2017) Patients who are medically and psychologically stable, motivated to change and willing to make progress with weight change should be seen in an outpatient setting (8).</p>

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			whose motivation may vary at different times.		
36	SCM4	People with an eating disorder should have access to evidence based psychological interventions	<p>There is good evidence that psychological interventions can be effective in the treatment of eating disorders.</p> <p>Psychological interventions are recommended within NICE guidance</p>	<p>There is considerable geographical variability in relation to access to specialist psychological treatments for eating disorders.</p>	
37	TEWSNHSFT	Inpatient treatment for males suffering from eating disorders.	Gender biases in provision of care and treatment need to be challenged.	<p>There is growing awareness and disquiet that men suffering from eating disorders are disadvantaged. There is unequal access to inpatient beds, with males having less access than females. Treatment programmes and clinical environments are often biased in favour of female orientated material.</p>	<ul style="list-style-type: none"> <li>• QED has supported work on identifying and highlighting the ways in which males are disadvantaged. This work could be drawn on and developed formally.</li> </ul>

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38	BEAT	The NICE Guideline on eating disorders in recommendations 1.1.5 and 1.1.10	Support for carers is also thought to vary significantly and their role in facilitating recovery is often crucial.		
39	BEAT	Coordination of care	<p>Given the typical age of onset for eating disorders and the high levels of co-morbidity it is common for patients to require treatment in more than one service at the same time and to require one or multiple transitions between services, including in different geographic areas. Given the complexity of eating disorders, including their medical and psychiatric risk, it is essential that care is planned and coordinated.</p> <p>This topic is mentioned in Recommendations 1.1.18, 1.8.1 and 1.11.11 of the NICE Guideline on eating disorders.</p>	<p>Beat has heard countless examples from callers to our Helpline and respondents to Beat surveys about seriously inadequate or non-existent care planning and coordination of care.</p> <p>Failure to deliver coordinated care has tragically led to the death of the patient on many occasions.</p> <p>This issue has been highlighted in a number of research studies, including - <a href="http://bjp.rcpsych.org/content/bjprcpsych/187/5/398.full.pdf">http://bjp.rcpsych.org/content/bjprcpsych/187/5/398.full.pdf</a>.</p>	CQC may collect data about coordinated care which could be used to monitor compliance, as long as this can be disaggregated to refer specifically to patients with an eating disorder.

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			<p>Also relevant are NICE Guidelines NG27 and NG43.</p>		
40	SCM 3	Co-ordination of care and transition between services	<p>The NICE committee expressed the view that service structures that facilitate a co-ordinated approach to care may lead to prompt identification of needs and this results in subsequent treatment and management of an eating disorder (and potentially of any comorbidities) at an earlier stage, before individuals require more resource intensive management.</p> <p>The NICE committee came to the consensus that when clear transition protocols are not in place, with adequate preparation for transfer of care, recovery can be hampered</p>	<p>Co-ordination of care and transition between care varies widely across the UK, and more emphasis on this area may lead to services being commissioned to help improve this.</p> <p>Currently some patients 'fall through the gaps'</p>	Co-ordination of care and transition

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41	SCM 5	Coordination of care for students with eating disorders across local and university services,	to support students transitioning between localities, on leave from uni, and on and placements.	Currently students are left with no support over the holidays periods if they seek ED treatment local to their university, or vice versa, leaving them with patchy or absent treatment and support. Improving this should help to avoid hospital admissions.	
42	SCM 6	Transitions	Patients with eating disorders find transitions difficult	Transitions present a time of risk for disengagement. Transitions occur in multiple directions; typically the CAMHS to adult services is cited as being the problem area, but it may also be from inpatient to outpatient care (and vice versa), medical to mental health etc. A number of Trusts have developed all age services to minimise transitions but it is not clear whether this is beneficial overall or addresses the problem and there are risks associated with all age provision that have not been evaluated.	NHS numbers may provide a mechanism for tracking patient pathways across provision. Outcomes in those in all age services could be compared with outcomes in those where transitions are needed.

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43	TEWSNHSFT	Involvement of patients and carers in their care plan.	NICE recommends that patients and their families should be actively involved in the care and treatment of their family member with an eating disorder.	We need to develop processes that support this greater level of involvement.	<ul style="list-style-type: none"> <li>• NICE 2017 NG69: Eating disorders: recognition and treatment.</li> <li>• Skills based caring for a loved one with an eating disorder: The new Maudsley method. Janet Treasure and Grainne Smith.</li> </ul>
44	SCM 2	The effective and safe management of people with Eating Disorders admitted into acute hospital settings for medical stabilisation.	It is acknowledged in the NICE guidelines and elsewhere that there is a high mortality rate in Eating Disorders due to malnutrition and physical issues. Improved liaison, specialist Eating Disorders input in the acute setting could lead to reduced time spent in hospital, reducing not only financial cost but impact on quality of life on both the individual and family/carers.	Although there are the both the adult and junior MARZIPAN guidelines, developed because of gaps identified, and some areas have local implementation groups (e.g. Sheffield adult services), there is sparse evidence that care and in particular nursing care is delivered in a systematic and evidence based way. The degree of partnership working between acute settings and local Eating Disorders services is variable.	Sheffield MARSIPAN Protocol 2014 Sheffield Health and Social Care Trust/Sheffield Teaching Hospital Trust Authors: Dr Ruth Walton, Consultant Psychiatrist in Eating Disorders Dr William Bennet, Consultant Physician / Endocrinologist Alison Bent, Specialist Community

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					Dietician Andrea Morrall, Clinical Nurse Specialist in Eating Disorders
<b>5. Additional areas</b>					
45	National Clinical Director for Obesity and Diabetes, NHS England	From a clinical perspective within my portfolio, eating disorders in people with Type 1 diabetes constitutes a particularly challenging scenario, with significant associated excess mortality risk.			
46	SCM 5	Establishment of MARSIPAN regional hubs and networks to ensure guidance is implemented.	To disseminate best practice and professional support to non-specialist practitioners regarding refeeding.	This should help save lives and reduce hospital stays, if the patient is refeed in the right way, and in a timely way, with the right support. .	



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47	TEWSNHSFT	Involvement of Occupational Therapy in care and treatment.	Occupational Therapy intervention is an important part of the care and treatment of people suffering from eating disorders, particularly severe eating disorders.	The committee for NG69: Eating disorders: recognition and treatment did not include an Occupational Therapist and Occupational Therapy is not included in the recommendations.	<ul style="list-style-type: none"> <li>• Liaise with Laura Lock, Lead Occupational Therapist, regarding how to take forward formal inclusion of Occupational Therapy interventions.</li> </ul>

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48	TEWSNHSFT	Psychological interventions for which there are no current Randomised Controlled Trials but for which there is a developing evidence base, e.g. Cognitive Analytic Therapy, Dialectical Behaviour Therapy, Compassion Focussed Therapy.			

49	BEAT	Multidisciplinary approach to treatment	A multidisciplinary approach to treatment is important given the complexity of eating disorders. It is advocated in recommendations 1.12.3, 1.1.15 and 1.3.1.	<p>Access to treatment delivered in a multidisciplinary way (including through teams which can benefit from the input of dietetics and psychiatry) is highly variable across England and the UK.</p> <p>Evidence about gaps in the specialist eating disorders workforce can be found here - <a href="http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf">http://www.rcpsych.ac.uk/files/pdfversion/CR170.pdf</a>.</p>	<p>Health Education England has recently published a Workforce strategy. This included an ambition to recruit an additional 30 Consultant psychiatrists for Children and young people’s eating disorders services. We expect that HEE will publish updates on progress against this.</p> <p>The HEE workforce strategy has tasked STPs with developing local workforce plans. Some of these plans may provide data at the local level on the skill mix of eating disorders services.</p> <p>The Access and waiting times for Children and young people with an eating disorder specified an indicative workforce mix which would be suitable for a CEDS-CYP service and a tool to enable commissioners and providers to calculate the staff required to meet local need. These specifications could be contrasted with the</p>
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					staff employed at CEDS-CYP services.
50	SCM 3	Training and competence	<p>NICE recommend appropriate training and competence for professionals working with eating disorders to ensure high standard of care is delivered and to increase the likelihood of people recovering from an eating disorder.</p> <p>The cost of providing training and monitoring/supervision of professional is relatively small, in comparison to the potential positive benefits (such as reduced harm, improved staff ability to recognise eating disorders through better sharing of information, better ability to communicate with the family and carers and the potential to reduce their burden)</p>	Professionals currently working with people with eating disorders have different levels of training and monitoring, and professionals delivering interventions may follow different protocols across the UK.	Training and competencies

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51	NHS Improvement, Medical Directorate - Patient Safety Team	Ensuring the safety of patients who need nasogastric feeding as part of the treatment of an eating disorder	Nasogastric tube feeding may be required as a life-saving intervention, but failure to confirm the tube has been correctly sited in the gastrointestinal before using it has led to a number of fatalities and serious harm.	NHS Improvement has issued advice and guidance that emphasises the importance of providing staff with competency-based training for confirming nasogastric tube placement via pH in the 'safe range' or using the 'four criteria' method of x-ray interpretation	Please see <a href="https://improvement.nhs.uk/news-alerts/nasogastric-tube-misplacement-continuing-risk-of-death-severe-harm/">https://improvement.nhs.uk/news-alerts/nasogastric-tube-misplacement-continuing-risk-of-death-severe-harm/</a> and <a href="https://improvement.nhs.uk/resources/resource-set-initial-placement-checks-nasogastric-and-oro-gastric-tubes/">https://improvement.nhs.uk/resources/resource-set-initial-placement-checks-nasogastric-and-oro-gastric-tubes/</a>
52	BEAT	Patients are able to access the full range of NICE-recommended therapies	<p>The NICE Guideline on eating disorders recommends a range of psychotherapies and stresses the importance of patient choice.</p> <p>It is important that services have staff who are trained and competent in the delivery of those forms of treatment, if this choice can be realised.</p>	Patients ability to access different forms of psychotherapy for their treatment is highly variable across the country. Despite the relatively strong evidence base for Family based therapy, there are services without any staff with expertise in the delivery of this therapy.	The MHSDS will hopefully include codes for each of the different NICE-concordant therapies and this could be used in future to monitor this.

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53	SCM 1	The outpatient treatment of people with eating disorders.	The great majority of people with an eating disorder are managed on an outpatient basis (as indicated in the new NICE guidance). Despite this, the topic overview focuses almost exclusively on inpatient treatment and especially on the management of very severely ill cases.	Unless there is emphasis on the delivery of outpatient treatment to people with eating disorders, there is a risk of doing a disservice to the great majority of cases. The best parallel is the treatment of anxiety disorders where inpatient treatment is needed for a minority of cases (severe OCD) but most people are managed on an outpatient basis. I recommend that the topic overview focuses primarily on outpatient treatment.	