# Eating disorders NICE quality standard

# **Draft for consultation**

November 2017

**This quality standard covers** assessment, treatment, monitoring and care for children, young people and adults with an eating disorder. It describes high-quality care in priority areas for improvement.

**It is for** commissioners, service providers, health, public health and social care practitioners, and the public.

This is the draft quality standard for consultation (from 29 November 2017 to 8 January 2018). The final quality standard is expected to publish in April 2018.

# **Quality statements**

<u>Statement 1</u> People with anorexia nervosa have a discussion about their options for first-line psychological treatment.

<u>Statement 2</u> People with binge eating disorder participate in guided self-help programmes as first-line psychological treatment.

<u>Statement 3</u> Children and young people with bulimia nervosa participate in bulimianervosa-focused family therapy.

<u>Statement 4</u> People with eating disorders and comorbidities have the impact of all their treatments monitored using outcome measures.

NICE has developed guidance and a quality standard on service user experience in adult mental health services (see the NICE pathway on <u>service user experience</u> in adult mental health services, which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing eating disorder services include:

- Transition from children's to adults' services (2016) NICE quality standard 140.
- Diabetes in adults (update, 2016) NICE quality standard 6.
- <u>Diabetes in children and young people</u> (2016) NICE quality standard 125.
- Anxiety disorders (2014) NICE quality standard 53.
- Depression in children and young people (2013) NICE quality standard 48.
- Self-harm (2013) NICE quality standard 34.
- Depression in adults (2011) NICE quality standard 8.

A full list of NICE quality standards is available from the <u>quality standards topic</u> <u>library</u>.

#### Questions for consultation

#### Questions about the quality standard

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

**Question 3** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

### Questions about the individual quality statements

**Question 4** There is no specific statement on access to services. Do you think this should be a key area for quality improvement? If so, how could quality of access to services be measured?

**Question 5** Statement 1 focuses on people with anorexia nervosa having a discussion about their options for first-line psychological treatment to reflect the options within NICE guideline NG69. Will this discussion on treatment options drive up quality improvement for people with anorexia nervosa? Please give reasons for your answer.

# Local practice case studies

**Question 6** Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to <a href="NICE local practice case studies">NICE local practice case studies</a> on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: First-line psychological treatments for people with anorexia nervosa

### Quality statement

People with anorexia nervosa have a discussion about their options for first-line psychological treatment.

#### Rationale

Healthcare professionals should discuss these 'talking therapies' with people with anorexia nervosa (and their parents or carer as appropriate) to help them choose which they would prefer. Patient choice is important during these discussions.

# Quality measures

#### Structure

Evidence of local arrangements to provide first-line psychological treatments for people with anorexia nervosa.

Data source: Local data collection, for example, service specifications.

#### **Process**

a) Proportion of adults with anorexia nervosa who have a documented discussion about first-line psychological treatment at diagnosis.

Numerator – the number in the denominator who have a documented discussion about first-line psychological treatment at diagnosis.

Denominator – the number of adults diagnosed with anorexia nervosa.

**Data source:** Local data collection, for example, patient records.

b) Proportion of children and young people with anorexia nervosa who have a documented discussion about anorexia-nervosa-focused family therapy as first-line psychological treatment at diagnosis.

Numerator – the number in the denominator who have a documented discussion about anorexia-nervosa-focused family therapy as first-line psychological treatment at diagnosis.

Denominator – the number of children and young people diagnosed with anorexia nervosa.

**Data source:** Local data collection, for example, patient records.

#### **Outcome**

Proportion of people with anorexia nervosa who complete first-line psychological treatment.

**Data source:** Local data collection, for example, patient records.

# What the quality statement means for different audiences

**Service providers** (such as community eating disorder teams, primary care, secondary care, tertiary care and non-NHS units) ensure that pathways are in place to access psychological treatment for anorexia nervosa. Service providers should also ensure that healthcare professionals have training in delivering these programmes, and supervision with monitoring of competency.

**Healthcare professionals** (such as therapists specialising in eating disorders) discuss options for first-line psychological treatment with people with anorexia nervosa and support them in making a decision.

Commissioners (such as clinical commissioning groups, NHS England and local authorities) ensure that they commission services with the capacity and expertise to deliver options for first-line psychological treatment for adults, children and young people with anorexia nervosa.

People with anorexia nervosa talk about their options for first psychological treatment with a healthcare professional. These options are also discussed with their family members or carers as appropriate. Treatments aim to help people feel comfortable around food, so that they can eat enough to reach a healthy weight and stay healthy.

# Source guidance

Eating disorders: recognition and treatment (2017) NICE guideline NG69 recommendations 1.3.4 and 1.3.10

#### Definitions of terms used in this quality statement

#### First-line psychological treatments

First-line psychological treatments for adults with anorexia nervosa include:

- individual CBT-ED
- MANTRA
- SSCM.

[NICE's guideline on <u>Eating disorders: recognition and treatment</u> recommendations 1.3.5, 1.3.6 and 1.3.7]

First-line psychological treatment for children and young people with anorexia nervosa is anorexia-nervosa-focused family therapy in children and young people. [NICE's guideline on <u>Eating disorders: recognition and treatment</u> recommendations 1.3.10 and 1.3.11]

# Equality and diversity considerations

People with anorexia may have difficulty in deciding on their treatment and in these cases healthcare professionals may need to offer their clinical opinion.

Quality statement 2: First-line psychological treatment for people with binge eating disorder

### Quality statement

People with binge eating disorder participate in guided self-help programmes as first-line psychological treatment.

#### Rationale

Guided self-help programmes for adults, young people and children with binge eating disorder can improve relapse rates and reduce binge eating frequency and its long-term impact on physical and psychological health. If guided self-help is unacceptable, contraindicated, or ineffective after 4 weeks, group CBT-ED can be provided as part of a stepped care approach.

# Quality measures

#### **Structure**

Evidence of local arrangements to provide guided self-help programmes as first-line psychological treatment for people with binge eating disorder.

**Data source:** Local data collection, for example, service specifications.

#### **Process**

Proportion of people with binge eating disorder who participate in guided self-help programmes as first-line psychological treatment at diagnosis.

Numerator –the number in the denominator who participate in guided self-help programmes as first-line psychological treatment at diagnosis.

Denominator –the number of people diagnosed with binge eating disorder.

**Data source:** Local data collection, for example, patient records.

#### Outcome

a) Binge eating frequency for people with binge eating disorder.

**Data source:** Local data collection, for example, <u>Eating Disorder Examination</u>

Questionnaire and patient records.

b) Relapse rates for people with binge eating disorder.

**Data source:** Local data collection, for example, <u>Eating Disorder Examination</u> <u>Questionnaire</u> and patient records.

c) Level of satisfaction with the person's ability to self-manage their binge eating disorder after attending a guided self-help programme.

Data source: Local data collection, for example, local patient surveys.

#### What the quality statement means for different audiences

**Service providers** (such as community providers, primary, secondary and tertiary care and non-NHS units) ensure that they have teams in place to deliver guided self-help programmes as a first-line psychological treatment for people with binge eating disorder and monitor treatment response. They should also ensure that healthcare professionals have training in delivering these programmes, and supervision with monitoring of competency.

**Healthcare professionals** (such as a therapist) deliver first-line psychological treatments for people with binge eating disorder and monitor treatment response.

**Commissioners** (such as clinical commissioning groups, NHS England and local authorities) ensure that they commission services with the capacity and expertise to deliver guided self-help programmes as first-line psychological treatment for people with binge eating disorder and monitor treatment response.

**People with binge eating disorder** take part in focused guided self-help programmes as the first psychological treatment. This includes working through a book about binge eating and short sessions with a healthcare professional to check on progress. Usually there are between 4 and 9 sessions that last about 20 minutes each.

#### Source guidance

<u>Eating disorders: recognition and treatment</u> (2017) NICE guideline NG69 recommendations 1.4.2 and 1.4.8

# Definition of terms used in this quality statement

#### Guided self-help programme for binge eating

Guided self-help programmes for binge eating should:

- use cognitive behavioural self-help materials
- focus on adherence to the self-help programme
- 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)
- focus exclusively on helping the person follow the programme.

[NICE's guideline on <u>Eating disorders: recognition and treatment</u> recommendation 1.4.3]

# Equality and diversity considerations

Self-help materials should be supplied in a format that suits the person's needs and preferences. They should be accessible to people who do not speak or read English, and should be culturally appropriate, age appropriate and gender appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's <u>Accessible Information Standard</u>.

# Quality statement 3: Bulimia-nervosa-focused family therapy

### Quality statement

Children and young people with bulimia nervosa participate in bulimia-nervosa focused family therapy (FT-BN).

#### Rationale

FT-BN has a positive effect on remission, binge eating frequency and reducing hospitalisation rates.

# Quality measures

#### **Structure**

Evidence of local arrangements to provide FT-BN for children and young people with bulimia nervosa.

Data source: Local data collection, for example, service specifications.

#### **Process**

Proportion of children and young people with bulimia nervosa who participate in FT-BN.

Numerator –the number in the denominator who participate in FT-BN at diagnosis.

Denominator –the number of children and young people diagnosed with bulimia nervosa.

Data source: Local data collection, for example, patient records.

#### **Outcome**

a) Binge eating frequency for children and young people with bulimia nervosa.

**Data source:** Local data collection, for example, <u>Eating Disorder Examination</u> <u>Questionnaire</u> and patient records.

b) Relapse rates for children and young people with bulimia nervosa.

**Data source:** Local data collection, for example, <u>Eating Disorder Examination</u> <u>Questionnaire</u> and patient records.

c) Level of satisfaction with the child or young person's ability to self-manage their bulimia nervosa after attending FT-BN.

**Data source:** Local data collection, for example, local patient surveys.

### What the quality statement means for different audiences

**Service providers** (such as community providers, primary, secondary and tertiary care and non-NHS units) ensure that they have teams in place to deliver FT-BN for children or young people with bulimia nervosa and monitor treatment response. They should also ensure that healthcare professionals have training in delivering this therapy and supervision with monitoring of competency.

Healthcare professionals (such as a therapist) deliver FT-BN for children or young people with bulimia nervosa and monitor treatment response. They should establish a good therapeutic relationship with the child or young person and their family members or carers, supporting and encouraging the family to help the child or young person to recover by self-monitoring of bulimic behaviours and involvement in discussions. Later and final treatment phases will also entail therapists supporting and encouraging family or carer involvement in plans for appropriate independence and relapse prevention.

**Commissioners** (such as clinical commissioning groups, NHS England and local authorities) ensure that they commission services with the capacity and expertise to deliver FT-BN for children and young people with bulimia nervosa and monitor treatment response.

Children and young people with bulimia nervosa take part in bulimia-nervosa focused family therapy. It involves working with a practitioner (for example a therapist) to explore the effects of bulimia nervosa and how their family can support them to get better. Usually there are between 18 and 20 sessions that last for 6 months.

#### Source guidance

<u>Eating disorders: recognition and treatment</u> (2017) NICE guideline NG69 recommendations 1.5.6.

# Definition of terms used in this quality statement

#### **Bulimia-nervosa-focused family therapy**

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
  - o 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's guideline on <u>Eating disorders: recognition and treatment</u> recommendation 1.5.7]

# **Quality statement 4: Monitoring treatment impact**

#### Quality statement

People with eating disorders and comorbidities have the impact of all their treatments monitored using outcome measures.

#### Rationale

Monitoring treatment impact and comorbidities and the effect they have on each other is important for the person and their continuity of care. When treatment is monitored between eating disorder specialists and other healthcare teams it can also lead to earlier and more appropriate treatment and management of associated physical or mental health problems (including long-term health problems such as diabetes).

# Quality measures

#### **Structure**

a) Evidence of the use of standardised outcome measures to monitor the impact of all of the treatments for people with eating disorders and comorbidities.

**Data source:** Local data collection, for example, contracts and service specifications. NHS England's (2013) <a href="NHS standard contract for specialised eating disorders (adults)">NHS standard contract for specialised eating disorders (adults)</a> includes details on jointly agreed outcomes.

b) Evidence of joint working arrangements (regular liaison and meetings to discuss care or treatment plans) between eating disorder specialists and other healthcare teams for people with eating disorders and comorbidities.

**Data source:** Local data collection, for example, contracts and service specifications. NHS England's (2013) <a href="NHS standard contract for specialised eating disorders (adults)">NHS standard contract for specialised eating disorders (adults)</a> includes details on collaborative working.

#### **Process**

Proportion of people with an eating disorder and comorbidities who have the impact of all their treatments monitored using outcome measures.

Numerator –the number in the denominator who have the impact of all their treatments monitored using outcome measures.

Denominator –the number of people diagnosed with an eating disorder and comorbidities who are having treatment.

**Data source:** Local data collection, for example, using the electronic hospital records and local primary care systems.

#### **Outcome**

Quality of life.

Data source: Local data collection, for example, using patient surveys.

### What the quality statement means for different audiences

**Service providers** (primary and secondary care) establish management structures to ensure that eating disorder specialists and other healthcare teams work closely together to monitor treatments for each condition and the potential impact they have on each other for people with eating disorders and any comorbidities.

Healthcare professionals (such as eating disorder specialists and professionals from other healthcare teams including diabetes services, mental health services and paediatric services) jointly agree and use outcome measures to monitor the effectiveness of treatments for each condition and the potential impact they have on each other. They should also have a clear plan on the support and monitoring required for each person and should share agreed goals and decisions, including any changes to treatment plans.

**Commissioners** (such as clinical commissioning groups, NHS England and local authorities) ensure that the services they commission work closely together by using outcome measures to monitor the treatments for each condition and the potential impact they have on each other for people with eating disorders and any comorbidities.

People with an eating disorder and another physical or mental health condition have the impact and effect of their treatment monitored by a specialist in eating

disorders and healthcare teams who are treating their other condition. Their teams should also share information.

# Source guidance

<u>Eating disorders: recognition and treatment</u> (2017) NICE guideline NG69 recommendations 1.8.1 and 1.8.2

# Definition of terms used in this quality statement

#### **Comorbidities**

Physical and mental health conditions often occurring in people with eating disorders include:

- anxiety
- borderline emotionally unstable personality disorder
- depression
- diabetes
- gastroenterological problems
- · renal problems
- substance and alcohol misuse.

[Information for the public (NICE guideline NG69) and expert opinion]

# About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about <u>how NICE quality standards are developed</u> is available from the NICE website.

See <u>quality standard advisory committees</u> on the website for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the <u>quality</u> standard's webpage

This quality standard has been incorporated into the NICE pathway on <u>eating</u> <u>disorders</u>.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references

to organisations or people responsible for commissioning or providing care that may be relevant only to England.

### Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- emergency readmissions of people with eating disorders within 30 days of discharge from hospital
- morbidity of people with eating disorders
- mortality of people with eating disorders
- length of hospital stay of people with eating disorders
- health-related quality of life of people with eating disorders
- eating disorder patient experience of primary, secondary and outpatient care.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- NHS outcomes framework 2016–17
- Public health outcomes framework for England, 2016–19.

# Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the <u>baseline assessment and resource impact tools</u> for the NICE guideline on eating disorders to help estimate local costs.

# Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate

unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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