Healthcare Improvement Scotland | SIGN Evidence-based clinical guidelines

SIGN 164

Eating disorders

A national clinical guideline

First published January 2022
Revised August 2022

NHS SCOTLAND

Key to evidence statements and recommendations

Levels of evidence

1^{++}	High-quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
1^{+}	Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias
1^{-}	Meta-analyses, systematic reviews, or RCTs with a high risk of bias
2^{++}	High-quality systematic reviews of case-control or cohort studies High-quality case-control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal
2^{+}	Well-conducted case-control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
2^{-}	Case-control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
3	Non-analytic studies, eg case reports, case series
4	Expert opinion

Recommendations

Some recommendations can be made with more certainty than others. The wording used in the recommendations in this guideline denotes the certainty with which the recommendation is made (the 'strength' of the recommendation).

The 'strength' of a recommendation takes into account the quality (level) of the evidence. Although higher-quality evidence is more likely to be associated with strong recommendations than lower-quality evidence, a particular level of quality does not automatically lead to a particular strength of recommendation.

Other factors that are taken into account when forming recommendations include: relevance to the NHS in Scotland; applicability of published evidence to the target population; consistency of the body of evidence; and the balance of benefits and harms of the options.

R For '**strong**' recommendations on interventions that '**should**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more good than harm. For '**strong**' recommendations on interventions that '**should not**' be used, the guideline development group is confident that, for the vast **majority** of people, the intervention (or interventions) will do more harm than good.

R For '**conditional**' recommendations on interventions that should be '**considered**', the guideline development group is confident that the intervention will do more good than harm for **most** patients. The choice of intervention is therefore more likely to vary depending on a person's values and preferences, and so the healthcare professional should spend more time discussing the options with the patient.

Good-practice points

✓ Recommended best practice based on the clinical experience of the guideline development group.

NICE has accredited the process used by Scottish Intercollegiate Guidelines Network to produce clinical guidelines. The accreditation term is valid until 31 March 2025 and is applicable to guidance produced using the processes described in SIGN 50: a guideline developer's handbook, 2019 edition (https://www.sign.ac.uk/assets/sign50_2019.pdf). More information on accreditation can be viewed at www.nice.org.uk/accreditation

Healthcare Improvement Scotland (HIS) is committed to equality and diversity and assesses all its publications for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation.

SIGN guidelines are produced using a standard methodology that has been equality impact assessed to ensure that these equality aims are addressed in every guideline. This methodology is set out in the current version of SIGN 50, our guideline manual, which can be found at www.sign.ac.uk/sign-50.html. The EQIA assessment of the manual can be seen at www.sign.ac.uk/assets/sign50eqia.pdf. The full report in paper form and/or alternative format is available on request from the Healthcare Improvement Scotland Equality and Diversity Officer.

Every care is taken to ensure that this publication is correct in every detail at the time of publication. However, in the event of errors or omissions corrections will be published in the web version of this document, which is the definitive version at all times. This version can be found on our website www.sign.ac.uk

Scottish Intercollegiate Guidelines Network

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www.sign.ac.uk

First published January 2022
Revised August 2022

978-1-909103-89-4

Citation text

Scottish Intercollegiate Guidelines Network (SIGN).
Eating disorders 2022. (SIGN publication no. 164). [January 2022].
Available from URL: http://www.sign.ac.uk

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1 Introduction

1 1 Introduction

1.1 The need for a guideline

Eating disorders are characterised by preoccupation with weight, shape and calorie balance. The term eating disorders may seem misleading: not all disorders of eating are 'eating disorders' and when an eating disorder diagnosis is made it implies that more than eating behaviour is disordered. Purging, overexercise and preoccupation with body image cause psychosocial and physical harm. The guideline includes evidence for the management of people with anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorders (BED).

Eating disorders typically begin in early to mid-adolescence, but can emerge at any age.[1-3] Lifetime prevalence of AN in the general population in Western countries is about 1% in women and 0.5% in men.[4] Prevalence of eating disorders in teenage girls is as high as 12%, with about 1% meeting criteria for AN, the disorder with the highest mortality of any psychiatric disorder.[4] The true prevalence may be underestimated as it has been found that half of those who meet diagnostic criteria in the community do not access treatment.[4] Anorexia nervosa and BN are more common among female than male individuals[5] and there are higher rates of disordered eating among people who identify as lesbian, gay, bisexual, transgender, queer (LGBTQ+), or non-binary, particularly in transgender people.[6] A high prevalence of eating disorders associated with people from minority ethnic groups was reported in a study of a community in South East London.[7] Other UK-based studies have reported lower referral rates, and that people with minority ethnic backgrounds are less likely to seek treatment than white people.[8,9]

Adolescents have higher rates of full recovery and lower mortality than adults (mean mortality 2% vs 5%).[10] With treatment, around 50% of people with AN achieve full functional recovery.[10]

The cycle of treatment, recovery and relapse can cause severe disruption to education, employment, professional development and lifetime earnings.[11] Caring for someone with a severe eating disorder can pose psychosocial and financial burdens on families. Within mental health services in 2015, the average annual financial cost of treating someone with an eating disorder was £8,850, but exceeded £100,000 when combined with treatment of physical consequences.[11]

Earlier Scottish guidance on the management of eating disorders lead to an expansion in the provision and quality of services in NHSScotland, however the guidance is now out of date.[12] In 2020 the Mental Welfare Commission (MWC) for Scotland undertook a themed visit of eating disorder services and identified inequalities in the provision of services, including access to psychological therapies, and gaps in care during transition between services.[13] It also showed there is wide variation in the organisation of services for people with eating disorders across Scotland. One of the recommendations from the report was for SIGN to produce a guideline on the efficacy of treatments for people with eating disorders. The MWC report was followed by a Scottish Government-commissioned national review of eating disorder services, which was published in June 2021.[14] The report resulted in a number of recommendations to improve care, including implementing the recommendations of this guideline. An implementation group has been established by Scottish Government to take forward the recommendations in the report.

This guideline draws on an evidence base, interpreted in the context of the needs of Scottish service users and incorporating their lived experience. Where appropriate, quantitative evidence has been supplemented with the findings from qualitative research studies. Recommendations are made not only about service provision but also about ways to address the lack of agreed outcome measures and associated data collection nationally, and to direct research, paving the way for a growth in evidence and good practice.

1.1.1 Patient and carer perspective

Patients and carers may have different perspectives on healthcare processes and outcomes from those of healthcare professionals. The involvement of patients and carers in guideline development is therefore important to ensure that guidelines reflect their needs and concerns and address issues that matter to them.

As part of the guideline development process, third-sector organisations were invited to submit feedback on the views of patients, carers and service users on the guideline topic for consideration by the guideline development group. People with lived experience of eating disorders (aged 16–25) and people who have a support/caring role were recruited through Beat and the Scottish Eating Disorders Interest Group (SEDIG) to attend an interactive group session to discuss their priorities for improvements in care. Their views and preferences were then considered by the guideline group.

Common issues raised by patient and carer groups and through research include:

- Using weight as the sole measure of illness severity and need for treatment, or of recovery, was seen as unhelpful, potentially preventing early access to treatment. It may even provide a perverse incentive to lose more weight.
- A preference for treatment to focus on emotional and self-image concerns rather than an exclusive focus on weight gain and physical health.
- A wish for patients to have more choice about the type of treatment they receive rather than this being dictated by local protocols.
- A need for better support during transitions between child and adolescent mental health service (CAMHS) and adult services, or between health boards, for example when moving away from home to university.
- The impact comorbidities can have on eating disorders and vice versa.
- The need to adapt services and treatments to be more inclusive of people from minority ethnic backgrounds, men, people with LGBTQ+ identities and those who are neurodivergent.
- The need for awareness and treatment of eating disorders during pregnancy and parenthood.
- A concern that while attention is paid to eating behaviour and purging behaviour the management of healthy exercise levels is often neglected.
- The need for follow-up support by primary care, social services and the third sector after discharge from NHS eating disorder services. This includes attention to the physical problems resulting from an eating disorder, such as fertility, and dental or bone health. It may also involve signposting to self-help materials and peer-support groups.
- The importance of a positive and hopeful attitude that individuals and carers can make meaningful improvements to their quality of life.

Information points, to support informed discussion with patients, their families and carers, are denoted throughout the guideline with the symbol ⓘ. Further information for patients, family and carers is in section 16.

1.2 Remit of the guideline

1.2.1 Overall objectives

This guideline provides recommendations based on current evidence for best practice in the management of people with eating disorders of all ages and gender groups, in any health or social care setting. Eating disorders covered are anorexia nervosa, bulimia nervosa and binge eating disorder. Advice for treating people with eating disorders which do not entirely meet formal diagnostic criteria is to follow guidance for the diagnosis most aligned with their difficulties. This guideline also includes management of 'eating disordered' psychopathology occurring in the context of type 1 diabetes mellitus.

The feeding disorder avoidant/restrictive food intake disorder (ARFID) was included in the evidence review as people with ARFID can be seen in a range of services, including eating disorder services. However, no evidence was found to support advice on management of patients with this condition. Similarly, no robust evidence was found on the management of autistic people with eating disorders. Expert advice on autism and eating disorders, including ARFID, is available in the Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE) (www.peacepathway.org). Advice on the assessment and management of autistic spectrum disorder can be found in SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders.[15]

A holistic and individualised approach to care is required. The guideline focuses on evidence-based therapies. Other therapies, such as arts therapies, dietetics, occupational therapy, physiotherapy and speech and language therapies, play an integral part in the management of patients with eating disorders, but a lack of robust research prevented their inclusion in an evidence-based guideline.

The remit excludes the management of obesity in the absence of a diagnosable eating disorder, and prevention of eating disorders, as both of these are substantial topics which warrant separate guidelines in their own right.

A mixed methods approach, using quantitative and qualitative evidence was applied where it was considered that qualitative studies would provide better insight into the needs of the population addressed in the key question *(see Annex 1)*.

1.2.2 Comorbidities to consider when managing patients with eating disorders

Common comorbidities and coexisting health issues which have been considered when reviewing the evidence for this guideline are:

- anxiety disorders
- autism spectrum disorder (ASD) (and autistic spectrum which is not experienced as a disorder but as a variant of normal mental health)
- complex trauma
- personality disorders (PD)
- depressive disorders
- obsessive-compulsive disorder (OCD)
- mental health conditions of pregnancy and the postnatal period
- post-traumatic stress disorder (PTSD)
- psychotic conditions including schizophrenia and bipolar psychoses
- substance and/or alcohol misuse
- type 1 diabetes mellitus
- other physical illnesses, particularly those where symptoms and signs affect body weight or where treatment might affect body weight, eg cystic fibrosis, thyroid abnormalities or inflammatory bowel disease.

1.2.3 Definitions and treatment outcomes

Evolving considerations about the nature and classification of eating disorders affect the precision with which treatments can be researched. In recent years major changes have been made to the classification of eating disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and the International Classification of Diseases (ICD 11).[16,17] Most treatments involve biological, behavioural and psychosocial elements, making it hard to attribute outcomes. Clinicians recognise that failure to precisely meet listed criteria does not automatically mean that patients' symptoms could not respond to a treatment.

Scottish eating disorders services specialise in those disorders sharing the core psychopathology of preoccupation with weight and shape. Thresholds for referral depend more on service availability than on diagnostic criteria, and clinicians are not obliged to ration care to those meeting formal criteria. Such criteria are commonly used to delineate research cohorts, however. DSM-5 and ICD 11 criteria discriminate between anorexia nervosa and bulimia nervosa on the basis of weight.[16,17] The hallmark of AN is significant weight loss, whilst those who are not underweight are diagnosed as having BN if they purge (induce vomiting or use laxatives) or exercise excessively after bingeing, but BED if they binge without purging.

The term diabulimia (not recognised in official diagnostic criteria) implies that causing calories to be excreted in the form of glycosuria and high blood glucose levels is analogous to purging. People with diabetes lose weight easily by omitting insulin rather than by restricting diet or energy deficit. Thirty to forty percent of young people with diabetes omit or reduce insulin with the intention of losing weight.[18] Longitudinal studies suggest an increase in eating disorders in people with type 1 diabetes mellitus.[19]

There is disagreement about what constitutes recovery from eating disorders, with consequent variation in outcome figures. Qualitative meta-analysis finds that recovered individuals value self-acceptance, autonomy and interpersonal relationships as much as reduced ED symptomatology.[20]

The evidence cited tends to use the expression 'child' to refer to prepubertal children and 'young people' to indicate either adolescents under the age of 18 or people in their teens and 20s. Some studies used mixed samples of people under and over 18 years of age, therefore use of these expressions in the guideline is colloquial rather than implying strict age cut offs.

Much of the research has been based in inpatient settings. Where this guideline refers to inpatients this indicates residential treatment in a unit that specialises in the management of eating disorders. Where the patient is treated in an acute medical hospital, a diabetic ward or a general psychiatric unit this is specified.

1.2.4 Target users of the guideline

This guideline will be of interest to primary, secondary and tertiary healthcare professionals including clinical psychologists, dietitians, endocrinologists, gastroenterologists, general practitioners (GPs), health visitors, nurses, art therapists, occupational therapists, physiotherapists, perinatal mental health clinicians, psychiatrists, social workers, speech and language therapists, teachers and university staff, as well as patients and their families and carers.

1.2.5 Patient and carer versions

Patient and carer versions of this guideline are available from the SIGN website, www.sign.ac.uk

1.2.6 Equality impact assessment

An equality impact assessment for the development of this guideline is available in the supporting material section for this guideline on the SIGN website, www.sign.ac.uk

1.3 Statement of intent

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results.

The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at through a process of shared decision making with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be documented in the patient's medical records at the time the relevant decision is taken.

1.3.1 Influence of financial and other interests

It has been recognised that financial or academic interests may have an influence on the interpretation of evidence from clinical studies.

It is not possible to completely eliminate any possible bias from these sources, nor even to quantify the degree of bias with any certainty. SIGN requires that all those involved in the work of guideline development should declare all financial and academic interests, whether direct or indirect, annually for as long as they are actively working with the organisation. By being explicit about the influences to which contributors are subjected, SIGN acknowledges the risk of bias and makes it possible for guideline users or reviewers to assess for themselves how likely it is that the conclusions and guideline recommendations are based on a biased interpretation of the evidence.

Signed copies of declaration of interests forms are retained by the SIGN Executive and a register of interests is available in the supporting material section for this guideline at www.sign.ac.uk

1.3.2 Prescribing of licenced medicines outwith their marketing authorisation

Recommendations within this guideline are based on the best clinical evidence. Some recommendations may be for medicines prescribed outwith the marketing authorisation (MA), also known as product licence. This is known as 'off-label' use.

With the exception of fluoxetine, which is licensed for use in patients with bulimia nervosa, medications used to treat patients with eating disorders are 'off label'.

Medicines may be prescribed 'off label' in the following circumstances:

- for an indication not specified within the marketing authorisation
- for administration via a different route
- for administration of a different dose
- for a different patient population.

An unlicensed medicine is a medicine which does not have MA for medicinal use in humans.

Generally 'off-label' prescribing of medicines becomes necessary if the clinical need cannot be met by licensed medicines within the marketing authorisation. Such use should be supported by appropriate evidence and experience.[21]

"Prescribing medicines outside the conditions of their marketing authorisation alters (and probably increases) the prescribers' professional responsibility and potential liability".[21]

The General Medical Council (GMC) recommends that when prescribing a medicine 'off label', doctors should:[22]

- Be satisfied that there is no suitably licensed medicine that will meet the patient's need.
- Be satisfied that there is sufficient evidence or experience of using the medicine to show its safety and efficacy
- Take responsibility for prescribing the medicine and for overseeing the patient's care, including monitoring the effects of the medicine, and any follow-up treatment, or ensure that arrangements are made for another suitable doctor to do so.
- Make a clear, accurate and legible record of all medicines prescribed and, when not following common practice, the reasons for prescribing an unlicensed medicine.

Non-medical prescribers should ensure that they are familiar with the legislative framework and their own professional prescribing standards.

Prior to any prescribing, the licensing status of a medication should be checked in the summary of product characteristics (www.medicines.org.uk). The prescriber must be competent, operate within the professional code of ethics of their statutory bodies and the prescribing practices of their employers.[23]

Prescribers routinely take age, gender and weight into account when prescribing, but the effect of medications on a starved adult body may not be same as on the body of a healthy child of the same weight.[24] Prescribers should also be aware of the potential for unconscious bias, and should consider possible pharmacogenetics differences in patients of different ethnic groups.

2 Key recommendations

The following recommendations were highlighted by the guideline development group as the key clinical recommendations that should be prioritised for implementation.

2.1 Early intervention

R **A pilot of an additional FREED service to complement existing eating disorders services may be considered. This would offer early intervention to young adults aged 16–25 with eating disorders of less than three years' duration.**

2.2 Support for family and carers

R **Formal carer support should be offered to all carers. This could draw on materials from Expert Carers Helping Others self help or Collaborative Carer Workshops.**

2.3 Achieving and maintaining recovery

R **Refeeding to an optimised healthy weight** (taking the patient's ethnicity and sex into consideration) **should be offered routinely to all patients with anorexia nervosa, both as a life saving measure and also as an adjunct to achieving an optimised weight and to reduce relapse.**

2.4 Psychological therapies

R **The following psychological therapies are recommended:**

- **Children and adolescents with anorexia nervosa should be offered family-based treatment.**
- **Adolescents with bulimia nervosa should be offered cognitive behavioural therapy or family-based treatment.**
- **Adolescents with binge eating disorder could be offered cognitive behavioural therapy, interpersonal psychotherapy or family-based interventions.**

R **Systemic family therapy and augmentative family-based treatment approaches could be considered for children and adolescents with anorexia nervosa where there are additional features such as severe OCD or high levels of expressed emotion.**

R **Adolescents with anorexia nervosa could be offered enhanced cognitive behavioural therapy** (CBT-E as per Fairburn's model)**, at a dosage of 20–40 weekly sessions, or other forms of transdiagnostic CBT for eating disorders.**

R **The following therapies should be used as first-line therapies for adults.**

- **Those with anorexia nervosa should be offered enhanced cognitive behavioural therapy or other forms of CBT.**
- **Those with bulimia nervosa should be offered cognitive behavioural therapy, preferably specially adapted CBT-E or CBT-BN.**
- **Those with binge eating disorder should be considered for cognitive behavioural therapy or interpersonal psychotherapy.**

R If cognitive behavioural therapy is ineffective, unsuitable or unacceptable for adults with anorexia nervosa, other therapeutic approaches could be considered, such as interpersonal psychotherapy, the Maudsley Model of Anorexia Treatment, Specialist Supportive Clinical Management, or focal psychodynamic therapy.

R If cognitive behavioural therapy is ineffective, unsuitable or unacceptable, in adults with bulimia nervosa, other treatment options could be considered, such as, interpersonal therapy, integrative cognitive-affective therapy, or schema therapy. Mentalisation-based therapy may be considered if the patient has comorbid borderline personality disorder.

2.5 Type 1 diabetes

R Integrated intensive specialist care with the combined involvement of diabetes professionals and mental health professionals with experience in managing eating disorders is recommended to support people with type 1 diabetes and an eating disorder or compulsive insulin omission for weight control. Some patients may benefit from a specialist inpatient eating disorders service.

R Healthcare professionals should consider managing control of insulin administration alongside psychological interventions to address motivation, distress tolerance and to build trusting relationships with professional and lay carers.

2.6 Training for healthcare professionals

R Teaching and training should be offered to all healthcare professionals to allow them to identify individuals with eating disorders, recognise potential variations in their profile of symptoms, and how diverse needs may impact treatment.

3 Framing the journey of care

3.1 Early intervention

One hallmark of eating disorders is that people see them as coping strategies and are, at best, ambivalent about change. It can therefore be years before a person with an eating disorder presents to services. Current NHS systems and pathways, including long waiting lists may compound delays.[25] Harms can accumulate during untreated disorder, particularly in AN, where prolonged starvation damages brain structure and function.[26] Recent findings from a national review of eating disorders indicate the need for broader community awareness of the early signs of eating disorders, together with awareness of appropriate responses and referral pathways.[14]

There is no clear definition of early intervention. For patients with AN, the probability of recovery is highest early after diagnosis. As the duration of the eating disorder lengthens those with BN have a higher probability of recovery.[27] Every effort should be made to treat people with AN as soon as possible after symptom onset, bearing in mind that symptoms are likely to have been present for many months or years before presentation at services.

The First Episode and Rapid Early intervention in Eating Disorders (FREED) service model was developed to provide early engagement with and intervention for people who had eating disorder symptoms of less than 3 years, and were aged 18–25 (later changed to 16–25). Its efficacy has been studied in 56 female patients, with two follow-up studies.[25,28,29] All of the patients offered FREED took up treatment compared to 74% in treatment as usual (TAU). Investigators suggest this may be due to the early engagement telephone call (<48 hours from referral). At 12 months the FREED group had significantly improved ED psychopathology as assessed by the eating disorder examination questionnaire (EDE-Q).[29] In the 2-year follow up, patients in the FREED service model attended more treatment sessions and had clinically relevant greater increase in body mass index (BMI).[28] Eating disorder psychopathology was not measured so changes at follow up could not be assessed. It appeared that patients in the FREED group required less inpatient treatment.[28] Fifty-nine percent reached healthy weight by 12 months compared to 17% of the audit group and 70% had scores on EDE-Q at 12 months which were below the clinical cut off.[29] 3 2+

The FREED model was established as an additional service so did not appear to affect waiting times for patients receiving TAU (ie those who were older than 25 or had longer duration of illness than 3 years).[25] This model carries considerable cost implications which should be balanced against the cost of patients becoming more entrenched in their illness and requiring longer and more intensive treatments. 3

R **A pilot of an additional FREED service to complement existing eating disorders services may be considered. This would offer early intervention to young adults aged 16–25 with eating disorders of less than three years' duration.**

3.2 Support for family and carers

Eating disorders impact the whole family and can cause significant distress. The parents and carers of adolescent patients may be asked to participate in family-based treatments which may even increase levels of distress and conflict on a temporary basis in the interests of longer-term recovery. Adult patients are asked to be the agents of their own recovery in partnership with professional and lay supports. The support then offered to family members has a different focus.

Parents and carers have been shown to experience high levels of emotion, caregiver burden, distress and difficulties coping.[30,31] The significant psychological impact on carers can lead to the presence of ineffective strategies for managing an eating disorder, which may unintentionally exacerbate patient distress and, in turn, eating disorder symptoms.[32]

All identified studies exploring support for parents and/or carers of adults with eating disorders were based on the cognitive interpersonal maintenance model of eating disorders and associated materials, using a range of delivery formats.[32,33] This included online delivery with low-level guidance from a clinician (Overcoming Anorexia Online (OAO)), self help consisting of written materials and videos, with and without a clinician, and/or carer coaching (Expert Carers Helping Others (ECHO)), and parent and carer workshops (Collaborative Carers Skills Workshop) over six sessions or an abbreviated two-session format.[34-38]

Compared to less intensive interventions OAO demonstrated greater reduction on carer distress.[39] A two-session carer workshop led to greater reduction in carer burden than those who did not receive the intervention.[38,40] When compared to TAU or active controls, such as psychoeducation, the evidence for these programmes is mixed. In a pilot randomised controlled trial (RCT) comparing Collaborative Carer Workshops to psychoeducation, no significant difference was found in any carer outcomes.[37] 1++ 1−

The largest body of evidence, and associated longer term follow up, is focused on ECHO. A pilot RCT comparing a combination of ECHO and TAU to TAU only found that ECHO led to a moderate increase in carer skills and a reduction in counter-productive caring behaviours at 12 months.[35] Another RCT of ECHO (including telephone coaching) compared to TAU only, found no significant difference in carer distress but significant reductions at 6 months in caregiver burden and a reduction in expressed emotion in favour of ECHO.[34] Differences between interventions did not extend to 12- or 24-month follow up.[36] 1− 1++

Engagement with the ECHO self-help materials varied from 21% to 75% across trials.[34,35] Two RCTs found no additional benefit in adding telephone coaching to ECHO self-help materials.[35,39] 1++ 1+

These trials included carers of adults and adolescents. No trials explored the use of this model with parents or carers of younger children.

R **Formal carer support should be offered to all carers. This could draw on materials from ECHO self help or Collaborative Carer Workshops.**

✓ Family and carer support can be provided without breaching patient confidentiality and should always be offered if carers are not involved in formal family work and signposted to families even if their loved one is not accessing services. Manuals are available for both clinicians and lay readers teaching the cognitive interpersonal skills used in ECHO and related models.[33]

✓ Clinical judgement on the applicability of ECHO self-help materials within CAMHS should be made on an individual basis. There may be some conflict between advice given to parents or carers using this model and advice provided by family-based therapies *(see section 5.1)*.

ⓘ Encourage the patient to build a supportive network, which may involve family, carers and/or friends, while respecting the individual's right to confidentiality.

3.3 Achieving and maintaining recovery

Defining recovery from a mental disorder can be a controversial task. It is acknowledged to mean more than failure to meet diagnostic criteria, which are themselves matters for philosophical debate and development. At the same time recovery need not mean a complete absence of all symptoms. The Recovery Movement advocates for a definition of recovery which is described and owned by the individual in the context of quality of life even in the presence of enduring symptoms. It is based on connectedness, hope and optimism, identity, meaning and purpose and empowerment (CHIME).[41]

Many patients with eating disorders prefer definitions of recovery which focus on quality of life rather than on being in the healthy weight range *(see section 1.2.3)*. However, from both the physical and psychological point of view, it is essential to provide nutrition for the brain to allow it to develop and function to live life to the full. The ability to accept a weight in the healthy range without being obliged to engage in mental and behavioural preoccupations is seen by most clinicians as a hallmark of true recovery. Supporting patients to achieve a healthy body should be considered a viable option at all times to support psychological change and improvement in quality of life.

In the evidence different outcome measures have been used as proxies for the concept of recovery. Where BMI is often used as a convenient numerical measure it is essential that this is not used in isolation as an indicator of recovery.

Psychological and pharmacological therapies that support patients to achieve a functional recovery are addressed in sections 4–11.

3.3.1 Acute refeeding, renutrition and maintaining a healthy weight

Patients with AN typically have an extreme fear of gaining weight, in association with altered body image that makes refeeding a difficult treatment for them and sometimes for their carers to witness or oversee. This is related to the disorder itself rather than the process of the treatment. Refeeding therefore has to be carried out in association with other treatment modalities to help the patient and carers cope with the behavioural and psychological aspects of the condition. Refeeding for children, adolescents and adults with acute illness is addressed by the Medical Emergencies in Eating Disorders: Guidance on Recognition and Management guidelines (MEED),[42] www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr233-medical-emergencies-in-eating-disorders-(meed)-guidance.pdf. The Age of Legal Capacity (Scotland) Act 1991 and the Mental Health (Care and Treatment) (Scotland) Act 2003 must be considered if patient consent is not given (*see Section 3.4*).[43,62]

Refeeding is a necessary intervention to prevent death and achieve weight gain, and can be conducted safely orally or using nasogastric feeding.[44-46] A higher BMI after feeding and a shorter duration of illness are associated with a lower rate of relapse.[44,45,47,48] While results showed that patients should be refed to an optimised weight, no absolute criteria for BMI were determined.[44,45,47,48] MEED recommends that oral food and fluids is the preferred first-line treatment option for refeeding, although sometimes nasogastric feeding or supplements may be required or preferred, in the short term.[42] 1+ 2+ 3 2− 4

MEED recommends that reversal of starvation or partial starvation should be developed and overseen by a specialist eating disorders dietitian.[42] 4

A systematic review and an additional small RCT concluded that, with proper management, refeeding carries few risks and is unlikely to be harmful.[45,46] 1+ 2+

R **Refeeding to an optimised healthy weight** (taking the patient's ethnicity and sex into consideration) **should be offered routinely to all patients with anorexia nervosa, both as a life saving measure and also as an adjunct to achieving an optimised weight and to reduce relapse.**

R **In acutely ill patients refer to MEED guideline to safely manage refeeding.**

✓ Nutritional goals should be set on a patient-by-patient basis after a holistic assessment of the patient's general physical and psychological condition, taking into account the patient's ethnicity, biological sex, genetics, personal dietary requirements, sensory sensitivities and cultural beliefs. This should be guided by an experienced specialist eating disorder dietitian or suitably qualified alternative healthcare professional.

3.3.2 Physical activity and exercise

A systematic review concluded that including supervised exercise training in the management of adult patients with AN is safe as it did not result in additional weight loss and may be of benefit in improving strength and psychological wellbeing. Exercise training was reported to improve strength and cardiovascular endurance despite causing no change in lean body mass. No significant impact on quality of life was reported, although, negative feelings about food and exercise were reduced. There was a reduction in anxiety and depression, improved body image, improved social behaviour, and a reduction in requirement for secret exercise.[49] 2++

An RCT found that a combination of cognitive behavioural therapy (CBT) and the Loughborough exercise and activity programme (LEAP) resulted in healthier attitudes towards exercise and improvements in BMI and ED psychopathology in people with AN.[50] 1+

If the issues of dysfunctional exercise related to an eating disorder and negative body image are not addressed, both of which are maintaining factors of each other and of an eating disorder, then there is greater risk of chronicity and relapse.

An RCT (n=207 adolescents and adult women with AN or atypical AN) of healthy exercise behaviour (HEB), which integrates elements of exercise-based therapy into a CBT approach, found that HEB resulted in significantly greater reductions in the severity of compulsive exercise compared to the TAU group. There were no significant differences regarding weight gain, eating disorder and general psychopathology, and emotional regulation.[51] 1+

Introducing exercise into the management of patients with AN carries potential physical risks to bones and heart, and the risk of playing into the need to burn calories. Patients require assessment and monitoring of their medical, nutritional and psychological status.[52] A systematic review addressing ways to enhance exercise programmes suggests that assessment and monitoring should take place in collaboration with the multidisciplinary team and the exercise programme should be supervised by a suitably qualified clinician, eg a specialist physiotherapist in mental health and eating disorders.[52] Including a psychoeducational component to the exercise can help patients develop healthy attitudes towards exercise and recognise when exercise is becoming problematic.[49] Further expert advice on how to manage exercise in adults with eating disorders is available in the Safe Exercise at Every Stage (SEES) guidance,[53] (www.safeexerciseateverystage.com). 4 2++

There is increasing recognition of eating disorders amongst athletes, dancers and participants of many sports.[54] Labels such as female athlete triad or relative energy deficiency in sport (RED-S) may mask the diagnosis of a serious eating disorder. Moreover, where athletes have trained to build muscle at the expense of fat, a normal BMI can mask malnutrition.

SEES also provides guidance for athletes with eating disorders, and a version addressing safe exercise for children and young people is in development.[54] The SEES guidance can be used to guide practice but does not replace specialist assessment and clinical reasoning.

R **Specialist-supervised exercise programmes should be offered to patients with anorexia nervosa as part of a comprehensive management programme, which includes a psychoeducation component.**

R **Where appropriate** (depending on cognitive function and patient's motivational status) **the inclusion and integration of the treatment of dysfunctional exercise/activity should be considered as part of a multidisciplinary treatment programme.**

R **Patients with anorexia nervosa participating in an exercise programme should be managed within a multidisciplinary team. Ideally, assessment and supervision should be carried out by a suitably qualified clinician, such as a specialist physiotherapist in eating disorders.**

✓ Healthcare professionals should refer to the Safe Exercise at Every Stage (SEES) guideline to support adults with anorexia participating in an exercise programme.

✓ In the treatment of eating disorders in athletes and dancers a return to high levels of physical exercise carries risks which should be acknowledged and carefully addressed and monitored. There is specific guidance from Safe Exercise at Every Stage.

3.3.3 Severe comorbid and complex eating disorders

For some patients treatments offered as first line may not be acceptable or effective for them due to underlying comorbid psychiatric conditions. For example people with AN who have the neuropsychological features of ASD or significant ASD traits are associated with poorer outcome and do not respond as well to traditional treatments.[55] Few trials have been identified in patients with ED and comorbidities. Trials in patients with comorbid eating disorder and borderline personality disorder (BPD) are discussed in sections 9.3.3, 10.2.2, and 10.2.5. 1+

Around 30% of patients with an eating disorder meet criteria for at least one PD.[56] Some features are common to both disorders, and it is possible that some are consequences of the eating disorder or its treatment, rather than primary features of a PD. Difficulty managing relationships with different clinicians is a challenging aspect of PD presentation, so supervision and joint working are essential.

✓ Alternative choices should be offered when first-line treatments are ineffective or unsuitable for those with moderate to severe comorbid psychiatric disorders. Choice of treatments should take into account therapeutic models that have an established evidence base in the treatment of comorbidities that have been shown to interfere with treatment outcomes in eating disorders (eg post-traumatic stress disorder, personality disorder, substance misuse). Assertive outreach that includes other input from psychiatric specialties and the Community Mental Health Team should be considered for those with an eating disorder and severe comorbid conditions.

✓ Where a patient has an eating disorder and a personality disorder, different specialist services need to work closely together to prevent either gaps or conflicting goals in the work of each service. Transitions may also need to be sensitively managed *(see section 3.5)*.

3.3.4 Follow-up interventions

The evidence for the efficacy of internet or mobile phone-based aftercare and relapse prevention for patients who are in remission is variable.[57-59] The benefit may be dependent on the therapeutic approach rather than the method of delivery. For example, CBT delivered via the internet or mobile phone was found to be helpful in a systematic review of 16 studies in a variety of mental disorders, four of which were in patients with and eating disorder.[58] 1++

✓ Patients may relapse after functional recovery if the recovery was dependent on one main support, such as therapy or medication. Care plans therefore need to take an individualised and holistic approach to ensure patients are equipped to maintain recovery.

ⓘ Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.

ⓘ Ensure the patient knows how to access support programmes, when needed, as they continue through their recovery journey *(see section 16.2)*.

3.4 Using the Mental Health Act to support care

Although the vast majority of people with an eating disorder take part in treatment voluntarily, sometimes the illness is too severe to allow this and the use of legislation is required. The European Convention on Human Rights (ECHR) guarantees specific rights and freedoms prohibiting unfair and harmful practices.[60] In Scotland, specific legal frameworks are in place which may allow restrictions of an individual's human rights as defined within the ECHR, such as the right to liberty (Article 5), whilst providing a framework for safeguards and protection of an individual's human rights.[60] These include the Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000.[61,62] Right to life (Article 2) is often referred to as an absolute right although there are some exceptions.[60] There are also necessary restrictions on the right to liberty (Article 5) which provides for the use of the Mental Health (Care and Treatment) (Scotland) Act 2003 in delivering treatment on a compulsory basis, either in the community or more usually in hospital where criteria are met.

When using the Mental (Care and Treatment) (Scotland) Act 2003 anyone who is taking action under the Act has to take account of the following 10 principles being paramount in any interventions imposed on the child under the Act: non-discrimination, equality, respect for diversity, reciprocity, informal care, participation, respect for carers, least restrictive alternative, benefit, and child welfare.[62] The presence of all the following criteria is essential in applying the Act and applies to children as well as adults:

- The person has a mental disorder.
- Medical treatment is available which could stop their condition getting worse, or help treat some of their symptoms.
- If that medical treatment was not provided, there would be a significant risk to the person or to others.
- Because of the person's mental disorder, their ability to make decisions about medical treatment is significantly impaired.
- The use of compulsory powers is necessary.

In applying these criteria under the Act nutrition can be considered as medical treatment.. In some situations, insulin for individuals with eating disorders, who also have insulin-treated diabetes mellitus may be medical treatment under the Act, for example, when a person is refusing or misusing the insulin because of the eating disorder. Significantly impaired decision-making ability (SIDMA) may be difficult to define in an individual with an eating disorder. Because of this, the Mental Welfare Commission for Scotland has published a series of good practice guidelines to help clinicians caring for people with eating disorders (www.mwcscot.org.uk/sites/default/files/2019-06/sidma.pdf).[63-67]

In using compulsory treatment when necessary for treatment of an eating disorder a systematic review found that there were comparable outcomes, in terms of weight and BMI, to informal treatment. However, a study found that patients who were detained tended to have a longer length of hospital stay. This may be because where compulsory treatment was used, patients had lower weight when admitted and had more complexity and comorbidity, with more previous admissions, not just related to the severity of the eating disorder.[68,69] 2+ 3

R **Clinicians should consider whether the Mental Health (Care and Treatment) (Scotland) Act 2003 needs to be invoked when a patient** (of any age) **declines treatment. There may be a responsibility to provide compulsory treatment if there is a risk to the person's life or to prevent significant deterioration to health and wellbeing.**

3.5 Transition

The transition of most concern in all health services is the transition for children and young people under the age of 18 into adult services. In the specialty of eating disorders the development and management of an eating disorder, as well as other major life transitions, are likely to occur around 18 years of age. There are, however, other important service transitions which require careful handling and benefit from attention to the same principles. These include geographical moves, and moves into and out of inpatient units as these are usually staffed by different teams from community services. 3

Four main themes on transition were identified in a scoping review of a variety of study types:[70]

- the importance of continuity and relationships with familiar clinicians
- the need for provision of accurate information to patients and parents
- the sharp drop in attendance at mental health services after the transition at age 18, and
- the benefits of structures to guide transition including overlap and parallel provisions.

Two of the studies in the scoping review, which focused on people with eating disorders were qualitative. These, and three other studies from the same research group, have been appraised as moderate quality.[71-75]

Two studies were conducted with service providers. One reported that denial, coupled with ambivalence to weight restoration, interfered with transition and that transition was a difficult time for parents of young adults with eating disorders.[72] It recommended that ongoing parental support was required to promote independence. The other suggested that there should be greater flexibility in the timing of transition, based on patients' and families' needs and readiness rather than age.[73] JBI 7/10

In the studies with service users it was reported that transfer procedures were inconsistent. Barriers included lack of knowledge from the family doctor, actual or perceived lack of access to adult care, and inflexible treatment options. Collaborative treatment approaches are recommended during paediatric treatment to foster autonomy and independence, better communication and information provision about adult services, and the maintenance of some element of external monitoring by primary care after transfer to adult services has occurred.[75] Young people experienced uncertainty about whether they or their parent should take responsibility for managing their eating, meals, and recovery once they have left paediatric care. Young adults want ongoing parental support during transfer in the form of emotional involvement, monitoring and supporting eating and behavioural changes, and help communicating with new professionals in the adult system. The support should be collaborative not coercive and controlling.[71] JBI 7/10

The participants in a UK-based study with young people and parents reported gaps in care when transitioning from CAMHS to adult services, which were unhelpful at that stage in their adolescence. Alternative suggestions were raising the age for transitions to 25, having a flexible approach dictated by need and not by age, or an integrated eating disorder service for all ages.[74] JBI 7/10

Guidance on transitions from CAMHS to adult services is provided by the Scottish Government.[76] A report from the Eating Disorders Faculty of the Royal College of Psychiatrists provides recommendations specifically for people with eating disorders transitioning not only from CAMHS to adult services, but also for all age ranges between all services, summarised in the following checklist:[77] 4

- be aware that transition is a time of increased risk
- ensure early identification and notification of the coming transfer
- involve family and carers
- offer flexible timing of transition
- ensure close links between services

- appoint a transition co-ordinator
- provide good information
- ensure clear protocols and pathways
- agree a patient-centred transition plan
- use multidisciplinary discharge planning meeting(s) to transition care
- agree an overlap period of joint working, and
- respect attachments and therapeutic alliances.

4

The report recommends the following:[77]

R **When a patient's age or geographical location necessitates a change of clinical team, the transition should be prepared, managed and followed up by clinicians in both services.**

R **A clinician should be identified as transition co-ordinator to supervise the process for several months before and after the move, and to communicate with all parties.**

R **A written transition plan should be drawn up in collaboration with patient, clinicians and carers, and copied to each party.**

✓ Healthcare professionals should remember that serious illness in childhood and adolescence often causes people to miss out on the psychosocial and even physical progress experienced by their healthy peers, and can delay their ability to function independently from the support of family and other carers. Family involvement may be beneficial beyond the usual age where this seems appropriate.

4 Therapeutic interventions

4.1 Treatment fidelity

The definition of recovery from eating disorders and the outcome measures used to describe recovery are discussed in sections 1.2.3 and 3.3. Ideally treatments could be matched to the particular outcomes most important to the individual concerned. Research is not currently either consistent or discriminative enough to allow this.

All studies included in this guideline measure outcomes for specified therapies delivered by appropriately qualified, trained and supervised clinicians.

✓ It is recommended that clinicians providing treatment for eating disorders should maximise treatment fidelity through regular ongoing training and clinical supervision, and should use standardised outcome measures to monitor outcomes.

ⓘ Discuss treatment plans with patients and allow them to share their ideas and concerns. Explain how a therapy works and why it may be appropriate for that individual.

ⓘ Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.

4.2 Delivering therapies remotely

Psychological therapies delivered remotely, either web-based or by video link are feasible, acceptable and may have similar efficacy as in-person consultations for the treatment of eating disorders, for adults, children and families *(see section 10.1.1)*.[78-80 81,82] Therapeutic alliance is similar to that of face-to-face consultations.[83] Early engagement through telephone calls is a component of the FREED early intervention model *(see section 3.1)*.[25] Video link for consultations and therapy has been widely used throughout the COVID-19 pandemic, with adaptations to therapies to support its use.[83,84] 1+ 1− 3 4

✓ The delivery of psychological assessments and treatment via videoconferencing could be offered as an adjunct or alternative to in-person sessions when there are barriers to accessing in-person sessions.

5 Children and adolescents with anorexia nervosa

5.1 Psychological therapies

Eating disorders commonly first present in childhood or adolescence, impacting significantly on the young person as well as their family members and/or carers. Despite this, there is a relative paucity of robust evidence available to guide the treatment of those aged under 18. It is recommended that further research be undertaken to evaluate the efficacy of a variety of potential therapeutic approaches.

5.1.1 Family-based therapy

Systematic reviews identified low-quality evidence that suggests all types of family therapy may be more effective than other treatments for reducing rates of remission and aiding weight gain.[85,86] 2++

Family-based treatment (FBT) is a manualised outpatient treatment that has been reported in older trials as an effective treatment for children and adolescents with AN, and is now an established practice.[87] In a more recent RCT (n=121, age 12-18 years) FBT was found to be superior to an individual outpatient therapy, adolescent-focused therapy (AFT), in effecting full remission at 6- and 12-month follow up. More participants were hospitalised during the treatment phase with AFT (37%) than FBT (15%), however the superiority of FBT was not sustained during the 12-month follow up.[85,86] 2++

An RCT (n=164, age 12–18 years) identified in a Cochrane review compared manualised FBT for patients with AN with systemic family therapy (SyFmTx).[85] There was no statistical difference between the two therapies at the end of treatment or at 12-month follow up. However, in the FBT group, the rate of weight gain was significantly greater at 8 weeks (p=0.003), hospital admissions were lower (FBT=8.3, SyFntX=21) and FBT cost less (FBT=$8,962, SyFmTx=$18,005).[85] 2++

One predictor that moderated the outcome effect at the end of treatment was OCD. Patients with higher OCD symptoms gained significantly more weight after SyFmTx than FBT (p=0.02) and patients with fewer OCD symptoms gained more weight after FBT than SyFmTx.[85] 2++

As family therapy and FBT for adolescents with AN are well-established practices, trials have moved on to study augmentative approaches to FBT designed to improve outcomes and consider moderators of outcome, rather than strengthening the evidence for family therapy and FBT.[87]

A systematic review of augmentative approaches in FBT included 30 studies.[87] There was low-quality evidence for the utility of augmentative FBT/family therapy for AN approaches, with improvements in weight and eating disorder symptoms. In particular, benefit was found in a separated parents/carers-only session for patients from families with higher expressed emotion, longer pretreatment illness duration or lower eating disorder or obsessive-compulsive symptom severity, and additional parent skill and mealtime-focused sessions for patients with lower early weight gain. Multifamily therapy (MFT) in addition to family therapy for AN was found to be superior (based on Russell-Morgan criteria of weight gain, return of menses and absence of bulimic symptoms) at the end of treatment compared to family therapy for AN alone, but this was not sustained at 6-month follow up.[87] 2++

5.1.2 Cognitive behavioural therapy

In a cohort of adolescents (n=46, age 13–17 years) with AN who were offered 40 sessions over 40 weeks of enhanced cognitive behavioural therapy for eating disorders (CBT-E) (as per Fairburn's model), 63% completed the full treatment without requiring any additional treatment, 19% did not respond to treatment and 17% stopped attending. In those who completed the treatment the mean weight gain was 8.6 kg, standard deviation 4.14, 95% confidence interval (CI) 7.03 to 10.18. 2+

There were also improvements in psychological outcomes. Improvements were maintained at 60-week follow up.[88] 2+

In another study 65.3% of the 29 adolescents who participated attained their BMI goal after 40 weeks of CBT-E (as per Fairburn's model).[89] 2+

Studies (outpatient and inpatient participants, aged 11–18 years) from an Italian research group reported adherence to treatment with 20 weekly sessions of CBT-E (as per Fairburn's model) of between 71% and 96%. Those who completed treatment had improved weight gain and psychological outcomes which were sustained at follow up (up to 60 weeks).[88,90,91] 2+

5.1.3 Other psychological therapies

There are a number of other psychological therapies available for children and adolescents with AN that require further research and investigation. While some of these are delivered as standalone therapies, others are commonly offered as adjunctive parallel interventions.

There were a number of small studies of possible psychological therapies for children and adolescents with AN (some of which have been shown to be effective for adults) which do not meet criteria for inclusion according to SIGN methodology. There was a lack of robust research evidence for the following psychological therapies in the treatment of AN in children and adolescents: AFT, dialectical behaviour therapy (DBT), interpersonal therapy (IPT), cognitive analytical therapy (CAT), acceptance and commitment therapy (ACT), group therapies, Supportive Specialist Clinical Management (SSCM), schema therapy, Radically Open Dialectical Behaviour Therapy (RO DBT), compassion-focused therapy (CFT), cognitive remediation therapy (CRT). These therapies could be considered for patients with AN, as part of a clinical trial.

5.1.4 Recommendations for psychological therapies

R **Children and adolescents with anorexia nervosa should be offered family-based treatment.**

R **Systemic family therapy, and augmented family-based treatment approaches could be considered for children and adolescents with anorexia nervosa where there are additional features such as severe OCD or high levels of expressed emotion.**

R **Adolescents with anorexia nervosa could be offered enhanced cognitive behavioural therapy** (CBT-E as per Fairburn's model)**, at a dosage of 20–40 weekly sessions, or other forms of transdiagnostic CBT for eating disorders.**

5.2 Pharmacological therapies

Evidence on the use of antidepressants (including fluoxetine) in adolescents with AN was of poor quality.[92,93] Antidepressants had no impact on weight gain and the impact on eating symptoms or psychopathology is unclear.[93] 1- 4

However, psychotropic medication, most often olanzapine or fluoxetine, can be prescribed for children and adolescents with eating disorders.[94] 3

6 Children and adolescents with bulimia nervosa

6.1 Psychological therapies

A meta-analysis of RCTs in the treatment of people with diagnosed BN concluded that psychotherapies in general, across the full age range, yielded moderate to large remission from binge eating and compensatory behaviors, and reductions in symptom severity at the end of treatment when compared with control groups. This was mainly based on trials in CBT.[95] Within this meta-analysis there were three RCTs in adolescents.[96-98] 1++

When compared to supportive psychotherapy (SPT), FBT adapted for bulimia nervosa (FBT-BN) achieved higher binge and purge abstinence rates at the end of treatment (39% versus 18% with SPT) (n=80, age 12–19 years). Abstinence rates for both groups dropped at 6-month follow up (29% FBT-BN versus 10% SPT), but FBT remained statistically more effective than SPT.[96] In further analysis of this RCT, no difference in treatment outcome was found between single or two-parent families.[99] 1+ 3

In adolescents with BN or partial BN (n=130, age 12–18 years) the rate of abstinence from binge and purging episodes was significantly higher with FBT-BN (39%) compared to CBT for adolescents (CBT-A) (19%) at the end of treatment and at 6-month follow up, but this difference was no longer significant at 12-month follow up.[97] 1++

A further study examined CBT versus psychodynamic therapy (PDT) in girls between 14 and 20 years old with BN or partial BN. At the end of the treatment, a third of participants in both arms no longer met criteria for an eating disorder diagnosis and rates of remission were stable at 12-month follow up.[98] 1++

R **Adolescents with bulimia nervosa should be offered cognitive behavioural therapy or family-based treatment adapted for bulimia nervosa.**

R **If cognitive behavioural therapy or family-based treatment are not acceptable, psychodynamic therapy could be considered for adolescents with bulimia nervosa.**

6.2 Pharmacological therapies

No specific evidence was identified on pharmacological therapies in children and young people under the age of 16. This, however, should not preclude their use for comorbid conditions, such as anxiety disorders, OCD and depression.

Fluoxetine has been found to be effective in adults with bulimia nervosa *(see section 10.4)*, and a systematic review identified evidence that found that in 16–18 year olds fluoxetine (60 mg/day) can reduce binge eating and purging behaviours and eating disorder psychopathology in the short term. Use of fluoxetine is associated with an increased risk of bleeding and an increased risk of suicidal or self-harming thinking or aggression in under 25s, particularly on initiation.[21,100] 1+ 4

Fluoxetine is licensed in 8–18 year olds for the treatment of major depression only, so use in young patients with BN is 'off label'.

R **Fluoxetine** (60 mg/day) **may be considered in the treatment of patients with bulimia nervosa, aged 16–18, for short-term use along with the offer of psychological therapy, and with monitoring for suicidal, self-harming or aggressive behaviours, particularly at initiation.**

7 Children and adolescents with binge eating disorder

7.1 Psychological therapies

No RCTs in any therapeutic modality, conducted specifically for BED in children and adolescents were identified.[101,102] 1++

Cognitive behavioural therapy and IPT have been shown to be effective in adults with BED, so may be considered for treatment of adolescents *(see section 10.1)*. Similarly family-based interventions have been shown to be effective for adolescents with bulimia nervosa and anorexia nervosa, so may be considered for treatment of adolescents with BED *(see sections 5.1 and 6.1)*.

R **Adolescents with binge eating disorder could be offered cognitive behavioural therapy, interpersonal psychotherapy or family-based interventions.**

7.2 Pharmacological therapies

No evidence was identified on pharmacological therapies specifically in children and adolescents with BED. Evidence in adults does not support its use in the management of patients with BED *(see section 11.4)*.

R **Pharmacological therapies should not be used in the management of children and adolescents with binge eating disorder.**

8 Children, adolescents and adults with type 1 diabetes

Eating problems are twice as common in people with type 1 diabetes than people without diabetes and are usually associated with bingeing and purging. Insulin omission may be used to induce hyperglycaemia to lose calories and avoid weight gain or facilitate weight loss. This is associated with an elevated glycated haemoglobin (HbA1c) level.[103] However, some patients may restrict carbohydrate to reduce insulin requirements resulting in weight loss which can present with hypoglycaemia. There are screening tools specifically for patients with diabetes and possible eating disorder, for example the Diabetes Eating Problems Survey Revised (DEPS-R) questionnaire.

✓ Assessment for the presence of eating disorders should be considered as part of the routine review of patients with type 1 diabetes.

✓ Healthcare professionals caring for people with diabetes and/or eating disorders should be aware of the common practice of insulin reduction to avoid weight gain. A high HbA1c level, recurrent diabetic ketoacidosis (DKA), poor engagement with healthcare, infrequent/absent self-blood glucose monitoring, and omission of quick-acting insulin are frequently observed in people with type 1 diabetes and eating disorders. Hospital admissions with DKA and elevated HbA1c are indicators of immediate and long-term risks to health.

For this guideline, only the specific problem of inappropriate insulin adjustment and omission has been assessed, as this changes the approach to diagnosis and treatment of these high-risk patients. The sections on binge eating disorder and bulimia nervosa *(sections 6, 7, 10 and 11)* may be relevant for people with type 2 diabetes.

8.1 Psychological therapies

A systematic review of observational studies and one RCT, all in adults, found that inpatient programmes were associated with moderate improvement in HbA1c control, whereas there was only a small improvement from outpatient programmes, compared to waiting list controls or treatment as usual.[103] The inpatient programmes, delivered in specialist eating disorders units, were for 3 to 4 months, and consisted of daily interventions, such as psychoeducation, CBT, family therapy and regular nurse supervision for insulin control. The outpatient trials were weekly therapy sessions for 6 weeks. Uptake for the outpatient sessions was poor. Four of the six studies included (inpatient and outpatient) reported improvement in Eating Disorder Inventory (EDI) scores at follow up (ranging from 1 month to 3 years).[103] 2+

R **Integrated intensive specialist care with the combined involvement of diabetes professionals and mental health professionals with experience in managing eating disorders is recommended to support people with type 1 diabetes and an eating disorder or compulsive insulin omission for weight control. Some patients may benefit from a specialist inpatient eating disorders service.**

R **Healthcare professionals should consider managing control of insulin administration alongside psychological interventions to address motivation, distress tolerance and to build trusting relationships with professional and lay carers.**

See section 3.4 for advice on the use of the Mental Health Act to support the management of patients with type 1 diabetes with an eating disorder where there is a significant risk of life-threatening complications, such as DKA.

8.2 Pharmacological therapies

No evidence was identified on pharmacological therapies for children or adults with type 1 diabetes and an eating disorder.

9 Adults with anorexia nervosa

Recovery from AN involves both physical and psychological components. The numerical nature of BMI makes it a convenient, objective measure and full recovery from the disorder by definition involves being able to tolerate a healthy weight and healthy behaviours around maintaining this. It is more difficult to numerically measure indices of psychological and psychosocial recovery. These facets of recovery are the most important to patients and their family and carers. Validated self-report scales are helpful but at present there is little agreement on the best measures to use.

Research evidence indicates that even the most effective treatments available are limited by high attrition rates. For some patients this may be due to an underlying psychiatric comorbiditiy *(see section 3.3.3)*. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. The therapies described below have a small evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering treatment models based on preliminary evidence.

9.1 First-line psychological therapy

9.1.1 Cognitive behavioural therapy

Cognitive behavioural therapy is an established therapy to which other therapies are often compared. A review concluded that, using standardised measures CBT led to improvements in BMI and eating disorder symptoms. CBT resulted in a positive effect on depressive symptoms, self esteem, negative thinking, interpersonal difficulties and mood, but not anxiety. It was also shown to have adequate acceptability and adherence rates. However, CBT did not demonstrate superiority over other therapies for patients with AN.[104] There is large variability in CBT format, content and administration.[104] — 4

When used as maintenance treatment for 88 people who had recovered from AN after hospital treatment, manualised CBT (average 38 sessions over a year) resulted in no relapse in 65% of the CBT group compared to 34% in those who received TAU.[105] — 2+

A systematic review of CBT versus third wave therapies (DBT, schema therapy, ACT, mindfulness-based therapy, and CFT), concluded that, due to the paucity of evidence for newer therapies, CBT should be considered the first choice of therapy for patients with AN.[106] Further evidence of CBT in comparison to other therapies can be found in sections 9.2 and 9.3. — 1+

A systematic review of RCTs and single-cohort pre-post-treatment studies of CBT-E found significant improvement. Patients with AN reported a large increase in weight or BMI during treatment and follow up.[107] Another systematic review (10 RCTs and 10 uncontrolled studies) found CBT-E to be effective for the full spectrum of eating disorders. This review included six of the RCTs from the former review.[108] Patients with all types of eating disorders responded well to CBT-E, including those with AN, with respect to improved BMI, reduced eating disorder behaviours and improved core psychopathology (overvaluation of shape and weight). The six studies with a homogeneous AN patient sample showed that CBT-E resulted in an increase in BMI.[108] — 2+

An RCT in patients with AN compared CBT-E with SSCM and with the Maudsley Model of Anorexia Treatment for Adults (MANTRA). The number of sessions was titrated according to BMI over 10 months (BMI<16 =40 sessions, 16 – 17.5 =30 sessions and >17.5 =20 sessions). All therapists were experienced clinical psychologists. Completion rates were around 60% in all treatments and all resulted in improvements in weight and eating disorder psychopathology. CBT-E was superior in helping patients achieve a healthy weight at 12-month follow up (59% compared to 47.5% with SSCM and 44% with MANTRA). All three therapies were considered valuable treatments for AN.[109] — 1++

9.2 Second-line psychological therapies

9.2.1 Interpersonal therapy and Specialist Supportive Clinical Management

An RCT and follow up study in patients with AN (BMI 14.5 to 19) comparing CBT, IPT and SSCM, (20 one-hour manual-based sessions conducted over ≥20 weeks) found that the different therapies had significantly different effects over time. Those in the CBT group had the most stable course. The SSCM group had the most immediate effect, with 75% reporting a reduction in AN features compared to 33% in the CBT group and 15% with IPT. IPT had the greater effect at long-term follow up (6.7 years), with a reduction in AN features in 64% of participants, compared to 41% with CBT and 42% with SSCM. This trial was poorly conducted, with concerns about randomisation, blinding and concealment methods.[110,111] 1-

9.2.2 Specialist Supportive Clinical Management

An RCT comparing CBT, IPT and SSCM showed SSCM to have the best immediate effect on patients with AN, with 42% reporting good outcomes at long-term follow up.[110,111] 1-

An RCT comparing CBT-E with SSCM and MANTRA *(see section 9.1.1)* showed similar completion results for all three therapies (60%) and a good effect over time with 47.5% of those in the SSCM group achieving a healthy weight at follow up.[109] 1++

SSCM was compared to MANTRA in two RCTs *(see section 9.2.3)*.[112,113] Over 12 months 19% of the SSCM group achieved a BMI over 18.5 (compared to 14% in the MANTRA group). More participants in the SSCM group achieved a normal EDE-Q score (73% compared to 59% in the MANTRA group).[112] In the second RCT 16.33% of the SSCM group were recovered at 12 months compared to 22.4% in the MANTRA group.[113] At 24-month follow up (with 79% participants) 28.3% of the SSCM group were recovered compared to 32.15% of the MANTRA group. 1++

9.2.3 Maudsley Model of Anorexia Treatment

The RCT comparing CBT-E with SSCM and MANTRA in patients with AN is described in section 9.1.1. Completion rates were around 60% for all treatments, and all resulted in improvements in weight and ED psychopathology. Forty-four percent of the MANTRA group achieved a healthy weight at 12-month follow up compared to 59% in the CBT-E group. All therapies were considered to be valuable treatments for AN.[109] 1++

Two further RCTs of MANTRA versus SSCM were conducted at the centre where MANTRA was developed. In the first, 72 participants (BMI >16.5) had a mean duration of illness of 6.6 years and over half had had previous treatment. All patients received 20 weekly individual sessions and four monthly follow-up sessions. Two additional sessions with family members were included and a dietetic assessment as required. For lower-weight patients (BMI <15) treatment could be extended for up to 30 sessions with four follow-up sessions. Treatment was provided by experienced eating disorder therapists. Patients in both arms improved significantly in terms of weight, eating disorder and other outcomes with no significant differences between them. The mean increase in weight from baseline to 12 months was 3.55 kg. Over the 12 months 14% of patients in the MANTRA arm and 19% of the SSCM arm achieved a BMI >18.5. Fifty-nine per cent of the MANTRA arm and 73% of the SSCM achieved a normal eating disorder examination (EDE) score over 12 months. The proportion of people achieving a normal BMI and normal EDE score was 14% in the MANTRA arm and 19% in the SSCM group. Patients in the MANTRA group were more likely to need additional inpatient or day care treatment ($p<0.004$).[112] 1++

In the second of the RCTs, 142 outpatients with AN or an eating disorder not otherwise specified (EDNOS) had 20 weekly individual sessions and four monthly follow-up sessions. This included patients with a BMI <15 who were given up to 30 sessions. Both treatments resulted in significant improvements in BMI, reductions in eating disorder symptomatology and distress, and clinical 1++

improvement over time. At 12 months 22.4% of those in the MANTRA arm and 16.33% of the SSCM arm were recovered (BMI >18.5 and normal EDE score). The differences were not statistically significant. Subgroup analysis found a trend for patients who received MANTRA to show greater BMI increase at 6 and 12 months. At the end of 12 months MANTRA was rated as more acceptable and credible than SSCM.[113] 1++

A further study produced follow-up data at 24 months, with 79% of the participants. Of these, the full recovery rate was 15% (MANTRA) and 28.3% (SSCM). No patients in the study needed additional intensive treatment (inpatient or day care). Subgroup analyses continued to suggest more severely unwell patients respond better to MANTRA.[114] 2++

9.2.4 Family therapy

Two studies, including adults up to the age of 27, rated in a Cochrane review as low quality, concluded that family therapies may be as effective as treatment as usual in the short term. Both studies had a small number of participants and potential bias. From the other six studies included in the review, one provided insufficient evidence to offer any advantage of family therapy over educational interventions and the other five (of poor quality) did not support family therapy over other psychological therapies. There was a lack of specificity about the theoretical underpinning of the family therapy approach in a number of the trials and therefore it could not determine whether there are differences between the various types of family therapy.[85] 1++

9.2.5 Focal psychodynamic therapy

The Anorexia Nervosa Treatment of OutPatients (ANTOP) study compared focal psychodynamic therapy (FPT) with either CBT-E or TAU (structured care from a family doctor) over 10 months (averaging 40 sessions each). Outpatient treatment of AN through specialist therapy (FPT or CBT-E) or TAU led to weight gain and reduced eating disorder psychopathology but there were no significant differences between the groups. At 12-month follow up mean BMI in all groups had increased. The proportion of patients recovering continued to increase after the end of treatment. The group receiving FPT had higher recovery rates (35%) compared to TAU (13%) and required fewer admissions. The study had a high treatment completion rate with 70% for FPT and 81% for CBT-E which was attributed to a clear framework for psychiatric and medical monitoring, brief inpatient treatment for those with a BMI <14, a brief nutrition guide and a family session. Patients in the FPT group gave positive ratings of their treatment experience.[115] 1+

9.3 Other psychological therapies

There are several other therapies available for people with AN that merit further research and investigation.[106] While some of these are delivered as standalone therapies, others are commonly offered as adjunctive parallel interventions.

9.3.1 Compassion-focused therapy

A study (patients with AN, n=19) introducing CFT into a standard CBT programme for people with eating disorders had encouraging results. While this approach showed better results for patients with bulimia, 33% of those with AN were considered recovered. There were significant improvements in eating disorder psychopathology during the treatment programme.[116] 3

9.3.2 Cognitive remediation therapy

Cognitive remediation therapy for AN was developed as an adjunct treatment to target set shifting and central coherence in patients with AN and to improve clinical outcome.

While small RCTs have reported some symptomatic benefits from CRT as an adjunct to CBT or TAU, more recent studies concluded that, other than a possible reduction in drop out rates, CRT was no more effective than the control.[117-119] 2+ 1+

9.3.3 Dialectical behaviour therapy

A small study (n=25, 13 with AN) comparing DBT with TAU in patients with eating disorders and substance abuse found DBT to be more effective at improving behavioural and attitudinal features related to eating disorders, substance misuse, negative mood regulation and depressive symptoms. These results were maintained at 6-month follow up.[120] 1-

In a pilot study of patients with eating disorders (n=147, 18 with AN) and BPD, conducted in a naturalistic setting, DBT was compared with CBT and both therapies were adjunctive to attendance at either outpatients or a day hospital. At the end of treatment DBT was shown to have a statistically significant effect on the symptoms of BPD, including depression, but had no significantly different effects on eating disorder psychopathology from the CBT.[121] See section 3.3.3 for further information on the management of patients with an eating disorder and BPD. 2-

9.4 Recommendations for psychological therapies

R **Enhanced cognitive behavioural therapy for eating disorders or other forms of cognitive behavioural therapy should be used as first-line therapy for adults with anorexia nervosa.**

R **If cognitive behavioural therapy is ineffective, unsuitable or unacceptable for adults with anorexia nervosa other therapeutic approaches could be considered, such as interpersonal psychotherapy, the Maudsley Model of Anorexia Treatment, Specialist Supportive Clinical Management, or focal psychodynamic therapy.**

✓ Dialectical behaviour therapy is a transdiagnostic treatment regime showing greater validity for people with eating disorders with comorbidities including substance misuse disorder and borderline personality disorder (emotionally unstable personality disorder). This approach could, therefore, be considered instead of cognitive behavioural therapy for this complex group.

✓ Other therapies such as cognitive analytical therapy, schema therapy, mentalisation-based therapy, Radically Open Dialectical Behaviour Therapy, could be considered for patients with anorexia nervosa, as part of a clinical trial.

9.5 Pharmacological therapies

Prescribing for patients with AN always requires consideration of the starved physiology of the patient, their low body weight and abnormal electrolytes due to purging behaviours.[24] Psychotropic and other medication carries risks to the heart and other organs so benefits must always be set against these, and as a result research in this field is scarce.

People with AN may need specific adjustments to medication prescribed for other conditions, both physical and psychiatric. It is assumed in most studies of psychotherapy for AN that patients will be taking psychotropic medications prescribed on a case-by-case basis by experienced specialists.

✓ All low-weight patients should be monitored particularly closely when psychotropic drugs are prescribed. A baseline electrocardiogram (ECG) and further monitoring can alert clinicians to avoidable dangers.

9.5.1 Antipsychotics

The rationale for using antipsychotic medication for AN is for the reduction of distress and obsessionality. The use of weight as a measure of its effectiveness is a proxy representing the fact that a patient needs to have acquired healthy psychological skills in order to achieve and maintain a healthier weight.

Meta-analysis of seven small studies of second-generation antipsychotics (olanzapine, risperidone and quetiapine) used weight gain as a proxy for overall holistic improvement. It did not find any significant difference between treatment and placebo.[122] 1++

A more recent and larger RCT of olanzapine did report statistically significant weight gain in adults with AN after 16 weeks compared with placebo.[123] No significant adverse effects were reported, and the patients on olanzapine had no metabolic adverse effects.[123] 1++

9.5.2 Cannabinoids

Use of dronabinol was associated with increased weight gain but also an increase in physical activity in one small RCT.[124,125] 1-

9.5.3 Oxytocin

Self-administered intranasal oxytocin resulted in a reduction in anxiety levels in response to food and eating for inpatients undergoing nutritional rehabilitation, in a small RCT.[126] Further studies into the benefit of this therapy are required before a recommendation can be made. 1+

9.5.4 Testosterone

One RCT reported less weight gain in women with AN after 24 weeks of testosterone compared to those given placebo.[127] 1+

9.5.5 Recommendations for pharmacological therapies

R **Olanzapine may be offered to adults with anorexia nervosa to support recovery but should not be offered as the sole treatment.**

✓ Once the patient is weight restored general guidelines on the management of obsessional symptomatology and treatment for depression, anxiety and other conditions can be followed.

✓ Any other medication selected for the symptomatic treatment of anorexia nervosa and comorbid conditions should be carefully monitored and audited if possible. Patients should be entered into available research trials, if they consent.

There is no available evidence on the safest medication for rapid tranquilisation. Older antipsychotics should be avoided, if possible, because of potentially dangerous side effects. Olanzapine is commonly used in this situation, as it is reasonably well tolerated in patients with anorexia nervosa.

10 Adults with bulimia nervosa

Evidence indicates that even the most effective treatments are limited for adults with BN. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. Those therapies described below have a limited evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering alternative treatment models with preliminary evidence.

10.1 First-line psychological therapies

10.1.1 Cognitive behavioural therapy

Most of the research identified on psychological therapies focused on CBT. It is often used as the standard comparator in trials of other therapies.

Cognitive behavioural therapy has been found to be effective in reducing symptoms of bulimia compared with TAU or waiting-list control (WLC).[128] Network meta-analysis of studies of treatment for people with BN indicated that those most likely to achieve full remission are individual CBT (specific to eating disorders) (odds ratio (OR) 3.89, 95% credible interval (CrI) 1.19 to 4.02) and guided self-help cognitive behavioural therapy (cGSH) (OR 3.81, 95% CrI 1.51 to 10.90) compared to TAU or WLC.[128] 1++

A 16-week, 20-session course of CBT adapted for BN (CBT-BN) was as effective if delivered by video link as face-to-face, in terms of retention rates and abstinence from binge eating and purging.[80] Reduction in binge eating was more rapid amongst those receiving face-to-face CBT. At follow up no differences were found between groups in the frequency of binge eating episodes, but purging frequency remained lower in those who had face-to-face CBT.[80] 1+

Another study found online CBT-BN was as effective as bibliotherapy compared with WLC in reduction of bulimic symptoms at the end of 20 weeks (abstinence from purging OR 7.2, p=0.02). The online CBT-BN consisted of patient training materials and 25 scheduled sessions of feedback with a therapist. At 1-year follow up improvements were seen in both conditions, with no statistical difference in outcomes (OR 1.0 to 1.4, p=0.99).[129] 1+

A CBT-based self-help programme delivered over the internet, and bibliotherapy, accompanied by email guidance, were equally effective in reducing binge eating and vomiting. At the end of treatment almost 20% were abstinent from both bingeing and purging symptoms. There were no significant differences between treatment conditions.[130] 1++

A trial of tailored ACT-influenced internet-based CBT, with daily written interaction with a therapist, also reported improvements in eating disorder symptoms (measured with the EDE-Q) compared to the WLC, with 53.3% of the treatment group achieving clinically significant improvement compared to 23.8% in the control group.[131] 1+

A further study found that an online CBT-based chat group was slower to have an impact than face-to-face CBT in reducing binge eating and purging, but improvements were seen over time so both had similar results at 1-year follow up. In both groups only 14–30% of individuals became abstinent. There was high failure to engage and high dropout rates for both.[132] 1+

In patients with either BN (n=31) or BED (n=78), CBT, cGSH and DBT were equally effective in reducing binge eating at 6- and 12-month follow up. CBT had a more rapid effect.[13] 1++ 1+

A small study also showed that intensive CBT had a more rapid response rate (within 4 weeks) in reducing bingeing behaviours and improved normalised eating behaviours than motivational interviewing.[134] There were no significant differences between the two treatments at the end of the therapy. 1+

After 5 months of treatment 15/34 patients who had enhanced CBT for BN had stopped binge eating and purging, compared to 2/34 who had psychoanalytic psychotherapy.[135] 1++

There were no significant differences between a 17-session outpatient course of integrated group and individual CBT-BN and emotional and social mind training (ESM). Each therapy improved global EDE scores. Adherence rates were higher amongst the ESM group.[136] 1+

Nineteen weeks of either CBT-E or integrative cognitive-affective therapy (ICAT) resulted in significant improvements in bulimic symptoms in both treatment groups at end of treatment and 4-month follow up. There was no statistical difference between intent to treat abstinence rates for CBT-E (22.5% at end of treatment and follow-up) and ICAT (37.5% at post treatment and 32.5% at follow-up).[137] 1+

One RCT found stepped care (starting with supervised self help) to be superior to CBT in reducing binge eating and compensatory behaviours. Results for abstinence at the end of treatment were 18% for CBT and 11% for stepped care, and 18% and 26% respectively at 1 year. Forty percent in the CBT group and 34% in stepped care also received fluoxetine during treatment.[134] 1+

10.2 Second-line psychological therapies

10.2.1 Interpersonal psychotherapy

Interpersonal therapy may be as efficacious as CBT, but CBT is associated with a more rapid impact. In one RCT 44.8% of the CBT-E participants reported no binge eating, vomiting or laxative misuse at the end of treatment compared with 21.7% in the IPT-BN group (adjusted OR 6.7, 95% CI 1.9 to 23.6).[138] At 60-week follow up EDE scores continued to improve for those receiving IPT to the extent that the difference between CBT-E and IPT was no longer statistically significant (adjusted mean difference in global EDE score 0.28, 95% CI -0.74 to 0.18). Depression reduced significantly alongside ED symptoms with both therapies.[138] 1+

10.2.2 Dialectical behavioural therapy

A study of 16 patients with BN and 46 with EDNOS, all with comorbid BPD, found that DBT delivered in a naturalistic setting improved behaviours related to BPD but did not improve dysfunctional eating.[121] Two further small studies from the research group found that after treatment DBT was more effective than the WLC in improving eating disorder behaviours (binge eating and purging) and ED attitudes (EDE global scores).[106] 2− 1−

10.2.3 Schema therapy

In an RCT of women (n=112) with BN or BED similar efficacy was found between schema therapy, CBT and appetite-focused CBT. Each resulted in a reduction in binge frequency at the end of the 6-month weekly treatment programme and at 1-year follow up. Across conditions, large effect sizes were found for improvement in binge eating, other eating disorder symptoms and overall functioning. At end of treatment, 60% of patients scored within one standard deviation of the community means for adult females on the EDE-12 global score, indicating a clinically significant change. This was maintained at 12-month follow up with 64% of the total sample within one standard deviation of community norms. The retention levels across the three groups was 83%.[139] 1+

10.2.4 Psychoanalytical/psychodynamic therapy

A systematic review identified two RCTs that compared psychodynamic therapy with CBT in people with BN. One of the studies found improvements from both CBT and psychoanalytic conditions at the end of treatment, although changes took place more rapidly in the CBT group. At 2 years' follow up, 44% in the CBT group and 15% in the psychoanalytic psychotherapy group had stopped binge eating and purging (OR 4.34, 95% CI 1.33 to 14.21). The authors concluded that psychoanalytic treatment may need to be augmented with more directive behavioural interventions to increase effectiveness.[140] 1++

10.2.5 Mentalisation-based therapy

An RCT in patients with unspecified eating disorder diagnoses and BPD reported a greater reduction in shape concern and weight concern in the eating disorder examination following mentalisation-based therapy for eating disorders (MBT-ED) compared to specialist supportive clinical management (SSCM-ED). At 6, 12 and 18 months there was a decline in eating disorder and BPD symptoms in both groups. Only 15 of the 68 participants completed the 18-month follow up. Adverse events, mostly self harm, were reported in 10 patients.[141] 1+

10.2.6 Compassion-focused therapy

Modest results for the use of CFT as a treatment adjunct to CBT were reported in a naturalistic pre-post study for a subset of 26 patients with BN, within a wider study of patients with mixed diagnoses. Seventy-three percent of those with BN were reported to have made clinically reliable and significant improvements by the end of treatment.[116] 2−

10.3 Recommendations for psychological therapies

R **Cognitive behavioural therapy, preferably in the specially adapted format for eating disorders or bulimia nervosa, should be used as first-line therapy for adults with bulimia nervosa.**

R **If cognitive behavioural therapy is ineffective, unsuitable or unacceptable in adults with bulimia nervosa other treatment options could be considered, such as interpersonal therapy, integrative cognitive-affective therapy, or schema therapy. Mentalisation-based therapy may be considered if the patient has comorbid borderline personality disorder.**

✓ Adjunctive therapeutic approaches could be considered to enhance outcomes of established treatments.

10.4 Pharmacological therapies

A systematic review of RCTs of medication, psychological interventions and a combination of both reported that psychological therapies provided short- and long-term benefit and there was also short-term benefit (between weeks 8 and 16) from fluoxetine.[142] Fluoxetine was shown to improve behaviours such as binge eating and purging, and overvaluation of weight and shape. A dosage of 60 mg daily was more effective than 20 mg. A smaller number of studies also showed a reduction in symptoms of BN with trazadone, fluvoxamine, tricyclic antidepressants (TCA), monoamine oxidase inhibitors (MAOI) and the antiepileptic medication topiramate, although further research is needed to confirm results. When compared to psychological interventions and self help, only interventions that incorporated medication were associated with any side effects. Reported side effects are common to any use of a selective serotonin reuptake inhibitor (SSRI).[142] 1+

In contrast, a subsequent smaller review concluded that the addition of medication to psychotherapy, primarily CBT for patients with BN did not increase the effectiveness of treatment when compared with CBT alone.[143] 3

A meta-analysis suggests some benefit from SSRI and TCA medication in reducing binge eating and purging symptoms, although effect sizes were small. There was an increase in remission rates with MAOIs, although dietary restrictions associated with their use may reduce acceptability and safety.[144] 1+

In an RCT comparing the use of different SSRIs over a period of 10 weeks, fluoxetine and fluvoxamine were effective in reducing binge eating and purging symptoms in patients with BN; fluoxetine (reduction in binge 75%, purge 68%) and fluvoxamine (reduction in binge 59%, purge 62%). Both were more effective than sertraline (reduction in binge 18% purge 0%). Despite high levels of side effects with fluoxetine, such as irritability and anxiety, there was no discontinuation from the study.[145] 1-

Fluoxetine is the only licensed medication for patients with BN in the UK.

R **Antidepressant medication should be considered as a short-term treatment for patients with bulimia nervosa or as an adjunct to psychological treatments.**

R **When considering pharmacological treatment for patients with bulimia nervosa fluoxetine, usually at a dose of 60 mg daily, should be the first choice. If selective serotonin reuptake inhibitors are contraindicated other antidepressant medications could be considered.**

11 Adults with binge eating disorder

Evidence indicates that even the most effective treatments are limited for adults with BED. If first-line treatments are not effective second-line or adjunctive treatment modalities may be offered. The therapies described below have a limited evidence base. It is recommended that further research be undertaken to evaluate efficacy when offering alternative treatment models with preliminary evidence.

Although sustained weight reduction may be an appropriate goal for some patients with comorbid clinically-significant obesity, pursuit of weight loss is recognised in psychological therapy for people with eating disorders as a powerful maintaining factor for eating disorder thinking and behaviours.[146] This suggests a potential conflict between treatment goals of active weight loss and reduction in eating disorder psychopathology, although in practice, effective treatment for binge eating will generally result in small but meaningful weight loss. Further research into the relationship between appropriate weight management interventions in obesity and effective treatment for eating disorders is needed, with qualitative studies which explore the lived experience of BED likely to be of particular value in trying to understand how these issues may be balanced effectively and how they affect quality of life. The main outcome for this guidance on pharmacological treatment for people with BED is reduction of eating disorder thinking and behaviours.

11.1 First-line psychological therapies

The focus of CBT, which is the most tested psychological therapy for BED, is on eliminating dieting due to its central role in increasing risk of binge eating. Psychological therapies do not directly focus on weight loss in those with BED but on improving a person's relationship with food regardless of their size, and may not result in reduction of BMI. They are generally likely to be more beneficial in addressing the eating disorder. Interventions with a primary focus on BMI reduction are ineffective in their primary aim, as people tend to regain the weight they have lost over follow up.[101,102,147] A number of studies of psychological therapies are authored by those who have formulated the therapeutic approach for BED. 1++

11.1.1 Cognitive behavioural therapy

Meta-analysis of studies of psychotherapies and structured self help, most of which were CBT, reported significant post-treatment reduction of binge eating episodes and abstinence from binge eating (pooled OR 9.9 and 8.9 respectively) compared with inactive controls (mainly waiting list). Reduction in eating disorder psychopathology was also significant in both. Compared to WLC the dropout rate was significantly increased in both groups (OR 1.9 for psychotherapy and 2.4 for self-help treatment). The quality of the evidence was graded as very low across treatment categories and there was a lack of data on long-term efficacy.[148] The medium-term effectiveness (extending up to 12-month follow up) has subsequently been confirmed for CBT and CBT self help.[149] 1++

Another meta-analysis reported benefits of CBT formats (therapist-led, partially therapist-led, structured self-help CBT, and cGSH) in reducing binge frequency and achieving abstinence compared to wait list controls. The most significant results were for therapist-led CBT (relative risk (RR) 4.95 for abstinence and a weekly reduction of 2.3 binges) which was rated as high-quality evidence.[101] CBT (in any format) has not shown a significant reduction in BMI.[101,148,149] The effects for depression are mixed across meta-analyses.[101,147,148] 1++

The comparative effectiveness of different levels of therapist involvement in CBT have also been examined. Few differences were found when comparing therapist-led, partially-led, and structured self-help CBT in binge eating outcomes, based on low-quality studies.[101] In one study, therapist-led CBT was associated with significantly greater binge abstinence and reductions in binge eating 1++

frequency than CBT self help at the end of treatment, but these differences were not significant at 12-month follow up.[102] More robust evidence is required to fully determine which mode of delivery is most effective.[102] Most of the studies with a therapist-led arm delivered treatment in groups rather than individually. 1++

An RCT which used therapists who were not experienced in eating disorders, in a population including those with binge eating and BED, found that the guided self-help group improved abstinence compared to TAU, at end of the 12-week treatment and 12-month follow-up period. There were also improvements in pattern of restraint, eating concern, shape concern, weight concern, depression, social adjustment, but not BMI.[150] 1−

One small study compared CBT to long-acting methylphenidate. Those in the methylphenidate group had weekly support from a psychiatrist in addition to the pharmacological treatment. Following 12 weeks of treatment both groups were found to have a significant reduction in objective binge eating episodes. The number of participants who were binge free in the last four weeks of treatment did not differ. There was a reduction in BMI in the methylphenidate group but not in the CBT group at the end of treatment. Results were maintained at 3-month follow up.[151] 1−

11.1.2 Interpersonal psychotherapy

Meta-analysis of two RCTs concluded modest support for IPT (group IPT versus group CBT, and individual IPT versus cGSH). Interpersonal psychotherapy was found to be to be as effective as CBT at the end of treatment and 12-month follow up for remission (risk difference -0.00, 95% CI -0.12 to 0.12), reduction in binge eating frequency (standardised mean difference -0.04, 95% CI -0.27 to 0.20) and reduction in BMI (mean difference -0.33, 95% CI -1.55 to 0.89).[147] There was insufficient data to perform meta-analysis on eating disorder psychopathology or symptoms of depression, and drop out was too high in one study to look at follow-up data beyond 12 months. 1++

11.2 Second-line psychological therapies

11.2.1 Dialectical behavioural therapy

A systematic review identified two small RCTs which reported benefit from DBT compared to WLC with fewer binge eating episodes, lower EDE scores and significantly greater rates of abstinence from binge eating at the end of treatment.[106] In a third RCT, when compared to an active group therapy, binge eating abstinence occurred more quickly with DBT (64%) compared to therapist-led group therapy (36%), although these differences disappeared at 12-month follow up.[106] Two further studies in participants with mixed ED diagnoses were included in the systematic review, which concluded that DBT is probably an efficacious treatment. 1+

After 10 weeks of treatment, DBT resulted in a significant reduction in BMI (standard deviation +3.49±1.94 vs. +1.93±1.22 kg/m^2, p<0.001), decreases in the binge eating scale (BES) and emotion regulation (measured by difficulties in emotion regulation scale (DERS)) compared to WLC. No follow-up data was available.[152] 1++

An RCT (n=71) reported significant reductions, with large effects sizes, in binge frequency from both DBT guided self help, DBT unguided self help or an unguided self-help self-esteem control at post treatment and 12-week follow up.[153] No differences were reported between groups. 1+

In patients with either BN (n=31) or BED (n=78), CBT, cGSH and DBT were equally effective in reducing binge eating at 6- and 12-month follow up. CBT achieved the quickest results. There were no notable changes in BMI from baseline to the end of treatment for the participants with BED.[133] 1++

11.2.2 Group psychodynamic interpersonal psychotherapy

Comparison of therapist-led group psychodynamic interpersonal psychotherapy (GPIP) and CBT to WLC found both treatments to outperform the control condition in reduction in bingeing and improved abstinence.[101] Both active interventions were found to be comparable and results were maintained at 12-month follow up. A stepped approach comprising 10 weeks of unguided self-help CBT then switching to either 16 weeks of 90-minute psychodynamic interpersonal groups or no further treatment, showed that the groups conferred no extra advantage post-treatment or at 6-month follow up. At 6-month follow up only 25% of participants were abstinent from binge eating, which did not differ from the control group. There was a significant reduction in attachment avoidance and interpersonal problems.[154] 1⁻

11.2.3 Brief strategic therapy

In an RCT (n=60) comparing brief strategic therapy (BST) with CBT statistical and clinical significance was achieved for both groups in global functioning and weight decrease at 12-month follow up. There was also a reduction in binge frequency in the BST group but not in the CBT group. Brief strategic therapy was superior in all three outcomes. The therapy was delivered by telephone over 7 months as an adjunct to a weight-loss programme in women with BED and comorbid obesity.[155] 1⁺

11.2.4 Schema therapy

In an RCT (n=112) of traditional CBT versus appetite-focused CBT (with additional focus on recognition and response to hunger and satiety cues) versus schema therapy (all 6 months of weekly sessions, followed by 6 months of approximately monthly sessions) there was a reduction in frequency of binge eating and improvement in other eating disorder symptoms and overall functioning across all three groups. Change in the frequency of binge eating at the end of all treatments was greater for those with BED than BN. At 12-month follow up no differences were found between groups in terms of binge frequency. The proportion of participants with BED or BN who met community norms on the EDE global score did not differ at the end of treatment or 12-month follow up.[139] 1⁺

11.2.5 Integrative cognitive-affective therapy

Integrative cognitive-affective therapy (ICAT) showed a similar efficacy to cGSH in patients with BED. After 17 weeks of treatment there was a significant reduction in binge eating, with abstinence rates of 57.1% for ICAT and 42.9% for cGSH. At 6-month follow up rates were 46.4% for ICAT and 42.9% for cGSH (including those who dropped out of treatment). Treatment adherence was higher with those having ICAT, which was conducted in individual sessions (87% vs 74%).[156] 1⁺⁺

11.2.6 Compassion-focused therapy

Only one pilot RCT (n=41) on CFT for people with BED was identified. A 3-week self-help course with CFT or behavioural therapy reduced mean weekly binge days compared to the WLC.[157] Another small RCT in 22 participants with mixed eating disorder diagnoses found benefit when CFT was used as an adjunct to treatment as usual.[158] 1⁻

11.3 Recommendations for psychological therapies

R **Cognitive behavioural therapy or interpersonal psychotherapy should be considered for first-line therapy for adults with binge eating disorder.**

R **If cognitive behavioural therapy or interpersonal psychotherapy are ineffective, unsuitable or unacceptable in adults with binge eating disorder other treatment options could be considered, such as dialectical-based therapy, integrative cognitive-affective therapy, brief strategic therapy or schema therapy.**

✓ People with binge eating disorder should be made aware that the focus of cognitive behavioural therapy is on eliminating dieting due to its central role in increasing risk of binge eating. Therapies do not directly focus on weight loss but on addressing the factors that result in a person having a difficult relationship with food, regardless of their size.

Those who wish to lose weight (and this is deemed medically appropriate) need to be informed that it is a therapy which may not result in large reductions of BMI, but that interventions with a primary focus on BMI reduction are generally ineffective in achieving this aim in the longer term.

✓ Adjunctive therapeutic approaches could be considered to enhance outcomes of established treatments.

11.4 Pharmacological therapies

The majority of the identified studies of pharmacological treatments for patients with BED were conducted in North American populations. Weight loss was one of the outcome measures. The majority of the proposed medications are licensed as weight loss agents or are likely to cause weight loss, often due to stimulant and/or appetite suppressant qualities. Stimulant drugs have been associated with high levels of unwanted side effects, some serious, and with risk of misuse within individuals to whom they are prescribed or diversion and misuse within the wider community

An RCT of fluoxetine in patients with BED showed remission rates at 12-month follow up of 3.7% for fluoxetine alone, 26.9% for CBT with fluoxetine, and 35.7% for CBT with placebo, suggesting that medication alone is not effective.[159] Analysis of moderating factors showed that core eating disorder psychopathology of overvaluation of weight and shape was more effectively treated by CBT than fluoxetine.[160] Meta-analysis of antidepressants in the treatment of patients with BED found that all but one study reported short-term outcomes (8 weeks or less). The single study that reported outcomes at 16 weeks did not show ongoing benefit.[161] 1++ 1+

Meta-analysis of psychological and medical treatments for patients with BED confirmed that psychological therapies were more effective than pharmacological therapies in reducing binge eating behaviours, eating disorder psychopathology and depression. Lisdexamfetamine (LDX) had a small effect on binge eating behaviours and weight reduction, but no effect on eating disorder psychopathology or depression. There is a lack of data on the safety of long-term prescribing.[148] 1+

In 10 out of 12 studies, adding medication to a psychotherapy, such as CBT, conferred no additional benefit in reduction of binge eating outcomes. Antiepileptic medications zonisamide and topiramate were reported as enhancing binge eating outcome reduction when used in conjunction with CBT. Discontinuation due to side effects was noted particularly with zonisamide. These were small, single trials and further research is required before a recommendation can be made. No trials of LDX were included in this review.[143] 3

Evidence in relation to the efficacy and safety of LDX in the treatment of patients with BED is reported in four RCTs carried out by the same group of researchers, and funded by the pharmaceutical company which manufactures LDX. Meta-analysis of these studies concluded that LDX at a dose of 50 mg and 70 mg/day produced a reduction in binge eating frequency statistically significantly greater than placebo in both treatment and relapse prevention trials. There were significantly higher levels of adverse events compared with placebo. Serious adverse events occurred in 3.9% of the LDX group compared to 3.2% placebo, with many resulting in withdrawal from the study.[162] 1−

Lisdexamfetamine is associated with serious physical harms, particularly to the cardiovascular system and its safety is still not ascertained for use during pregnancy.[21] A limitation of reported evidence is that research studies screen for substance misuse, hypertension, cardiovascular disease and diabetes, psychiatric comorbidity, and concurrent psychotropic medication. Patients with

these conditions are excluded although these comorbidities are very common in routine clinical care. Furthermore, during the trial patients would be closely monitored for any adverse effects, in a way that is unrealistic in routine care. The study samples represented only a small subgroup of the population of patients likely to present to primary and secondary care services in Scotland for BED. This group as a whole would be particularly vulnerable to cardiovascular harms.

The longest duration of use of LDX in these studies was 38 weeks and no information was identified on longer-term safety or effectiveness of its use in this indication. Studies examining whether any reduction in binge eating symptoms was maintained after medication withdrawal showed that any gains were lost once individuals were off medication, suggesting that long-term prescribing would be required. The concern about adverse effects and misuse of medications which would potentially require long-term prescription suggests that safety data for long-term use should be available before recommendations are made.

Other studies identified were placebo controlled trials of medications either licensed for weight loss, or likely to reduce weight including:

- a novel opioid receptor antagonist,[163]
- sibutramine, a stimulant drug licenced for weight loss and chemically related to amphetamines, withdrawn due to increased risk of cerebrovascular and cardiovascular disease in people with heart disease,[164]
- rimonibant, a canabinoid receptor inverse agonist used as an appetite suppressant and weight loss medication, withdrawn due to increased risk of anxiety and depressive symptoms and some reported suicides of people taking this medication,[165]
- orlistat, a weight-loss agent,[166]
- a combination of the stimulant phentermine and the antiepileptic medication topiramate,[167]
- a combination of opiate receptor antagonist naltrexone and serotonin and noradrenaline reuptake inhibitor bupropion, which is used as an anti-obesity medication, as an antidepressant and in ADHD, and[168]
- bupropion.[169]

1+
1++
1−

None showed a statistically significant advantage over placebo for reduction in binge eating disorder symptoms. Orlistat and bupropion were shown to produce weight loss over the study duration only.[166,169]

R **Medication is not recommended either as an alternative or as an adjunct to psychological treatment for patients with binge eating disorder.**

✓ In patients with binge eating disorders medication should be considered in the treatment of comorbid conditions, with appropriate assessments of underlying risk factors, in particular cardiovascular and metabolic vulnerabilities.

12 Bone mineral density

Women with AN are likely to have an increased fracture risk of 150–300% due to significantly lower bone mineral density (BMD) values than healthy control women.[170] Bone mineral density is the best measure of the strength and health of bones, but there is not a direct relationship between biomarkers of bone turnover, BMD and fracture incidence, which is the outcome of concern.

Studies in people who do not have an eating disorder show that improved BMD results in increased bone strength and a reduction in fracture risk.[171] Achieving a healthy weight and, in women, the return of menstruation, are beneficial to bones and the strongest predictors of an increase in BMD. This is particularly important in adolescents, in helping them to achieve their full potential for bone development.[172] One study found that male adolescents with AN who achieve weight gain but remain underweight may experience further BMD loss, unlike their weight-restored counterparts (BMI ≥ 19 kg/m^2), who show a significant increase in BMD and bone mineral accrual rates that double those of healthy male adolescents.[172] — 4, 2+

Refeeding to normal weight has a low incidence of physical side effects and over time can achieve meaningful increases in BMD, whereas pharmacological interventions such as bisphosphonates and hormone replacement achieve limited improvements in the absence of weight restoration, and, given the long half life of bisphosphonates, the long-term side effects in adolescents and premenopausal women are unknown.[173] Full nutrition should therefore be considered the primary therapy to improve bone integrity.[172] Progress can be slow, with studies showing improvement at 16-month follow up.[172] First-line management should be renutrition but, due to the enduring nature of AN, alternative therapies should be available when this is not realistic.[173] — 2+, 2++

No RCTs were identified addressing pharmacological therapies to increase BMD in males with AN.[173] For adult women, the most significant increases in BMD were from bisphosphonate therapy. No significant increase in BMD was observed following administration of oral contraceptives, transdermal testosterone or oral dehydroepiandrosterone (DHEA) alone. Conversely, 100 µg of 17-β estradiol (with cyclic progesterone) administered transdermally did increase spinal and hip BMD in mature adolescents with AN.[173] — 2++

The long-term effects of bisphosphonates are currently unknown and an inadequate number of trials exist to confirm their safety. Although bisphosphonates are effective in increasing BMD, fractures can still occur due to reduced tensile strength. Bisphosphonate use is also associated with an increased occurrence of atypical femoral fractures, osteonecrosis of the jaw and upper gastrointestinal adverse effects.[171] Due to potential risk to the foetus bisphosphonates are contraindicated in women who have the potential to become pregnant.[21] — 4

No correlation was found between calcium and/or vitamin D intake and BMD in patients with AN. Vitamin D and calcium supplements are not sufficient to reverse bone loss on their own, but replacement should still be regarded as important in patients with a proven deficiency, particularly if they are undergoing other forms of treatment.[173] — 2++

A small study on the efficacy of jumping exercise to improve bone mineral density in adolescents with AN found no benefit.[174] More trials are needed before recommendations on exercise for improving BMD can be made. Advice on exercise to reduce the risk of osteoporosis in people with AN, produced by the Physiotherapy Eating Disorder Professional Network is available [175] (cpmh.csp.org.uk/content/physiotherapy-eating-disorders). — 1+

No evidence was identified on the value or frequency of dual-energy X-ray absorptiometry (DXA) scanning in patients with AN and lower BMD.

R **Weight restoration should be offered to patients, with low-weight anorexia, regardless of gender identity and age, as part of a holistic programme of treatment, to improve bone mineral density.**

R **Treatment with bisphosphonates or oestrogen to prevent loss of or restore bone mineral density and so reduce fracture risk should not be considered as treatment modalities on their own, but could be used as a supportive treatment. Benefits and risks should be discussed with the patient, and those who receive treatment should be closely monitored by experts in eating disorders and bone metabolism.**

R **Bisphosphonate treatment is not recommended for younger patients due to its teratogenic side effects and long half life.**

✓ The restoration of healthy nutrition will be reflected in normal body mass index. This is essential for optimal brain development and the health of other systems, such as the skeleton. Weight restoration is very difficult psychologically for patients. It is therefore essential that this is managed within a therapeutic setting ensuring that the holistic needs of the patient are met.

✓ Before starting any hormonal treatment for low bone mineral density in a patient with anorexia nervosa clinicians should seek advice from a paediatric, endocrinological or bone specialist and co-ordinate treatment with the eating disorders team.

✓ Men are also at risk of low bone mineral density but there is a lack of evidence on treatments other than weight restoration. Those who have persistent low bone mineral density should be referred to a specialist in bone metabolism in consultation with an eating disorder specialist.

13 Severe and enduring eating disorders

The course of an ED is always individual and although the average time to recovery is 7 years, there is huge variation. Some patients with eating disorders may not respond to a well-delivered course of an evidence-based treatment. Around a third of people with AN and BN continue to live with their eating disorder after this protracted time.[176] However, some recoveries are reported after more than 20 years.[176] More severe eating disorder symptoms, poorer psychological function and work and social wellbeing, alongside more lifetime hospitalisations, are associated with people with AN of longer than 7 years' duration and a high level of reported distress, compared to those of a duration of under 3 years. In people with illness of longer duration fewer changes were found to occur over a 12-month period, especially in relation to work and social adjustment.[177] 3

A recent meta-analysis, however, did not find a relationship between duration of an eating disorder and treatment outcome.[178] Association remained unclear due to heterogeneity across studies, so the authors advocated for continuing to offer intervention for those with a long course of eating disorder in the context of ongoing research. This seems particularly important as there is the potential for the terms used to define longstanding eating disorders (eg chronic or treatment resistant) to inappropriately result in loss of hope and unsuitable discharge from all treatment, as well as increasing stigma. 2++

There is no consensus on how to most appropriately define enduring eating disorders.[179] In this guideline the term 'severe and enduring eating disorder' (SE-ED) has been used, and studies have been reviewed which primarily meet the definition 'duration of eating disorder of at least 7 years or more'. A systematic review identified 'severe and enduring' as the second most common descriptive term used in studies of SE-ED (the most common being chronic, but there was concern this could be translated to mean incurable).[179] The systematic review identified that most research used duration of disorder as the sole criteria or as part of other classifications, and at least 7 years was the most common period. Although empirically-tested multidimensional criteria has recently been proposed, a limitation is that duration is defined as more than 3 years.[180,181] This is a significantly shorter course than is the case for most adults with eating disorders.

A systematic review of treatments for people with SE-ED found only small RCTs, observational and case studies.[182] The studies of pharmacological therapies and brain stimulation therapies were small, making it difficult to draw meaningful conclusions. 2++

Inpatient treatments, which consisted of individual or group CBT and, in two studies, nutritional plans for weight gain, reported improvements in eating disorder symptoms and weight restoration during treatment. The largest follow-up study (n=70) reported weight increase during the 2-year follow up. This study also found a decrease in binge eating behaviours during treatment, but not during follow up. Results of inpatient treatments across the studies during follow up were inconsistent. However, studies of day and outpatient treatment demonstrated improvements in symptoms both during treatment and follow up.[182] 2++

In one RCT (n=63) of outpatient treatment, patients were randomised to either adapted CBT-AN or adapted SSCM. The therapies were modified to prioritise harm minimisation and quality of life. Patients in both groups showed overall, significant improvements on all primary outcome measures (eating disorder quality of life, depression, and social adjustment). At the end of treatment, 6-month and 12-month follow up they also showed improvements in the secondary outcome measures of BMI, eating disorder psychopathology, and readiness to recover. Retention rates for both treatments were high (87% overall). There were no differences between groups at the end of treatment on any outcome measure or healthcare utilisation.[183] 1+

Further study of the sample group in the RCT reported that:

- Those with AN purging subtype and the worst scores for eating disorder quality of life were less likely to complete treatment.[184]
- Weight restoration and reduction in eating disorder symptoms during treatment improved current and future quality of life.[185]
- Adapted CBT-AN was more beneficial than adapted SSCM when participants showed greater ED symptomatology, more depression, or presented with an AN binge-purge subtype.[184]
- For both therapies the early formation of a strong patient-professional alliance predicted improvement in eating disorder symptomatology, but not in weight or depressive symptoms.[186,187]

3

The underlying neurological characteristics of people with enduring AN are similar to those of autistic people, so neurological traits need to be taken into account when considering appropriate treatment.[55]

1+

Based on the limited evidence available people with SE-ED may respond both to traditional treatment approaches and to those specifically modified especially if they are targeted at enhancing patient engagement.[182,183] However, there is a lack of evidence to guide clinical practice, particularly for eating disorders other than AN.

It may be helpful to move from active targeting of eating disorder symptoms to a more holistic approach, concentrated on optimising and maintaining a better quality of life and wellbeing, whilst minimising the negative impact of the eating disorder as far as possible. There is no evidence to inform when this shift should occur or exactly what form it may take.[155] It may be that part of this involves the modification of goals which focus on smaller steps that aim to maximise safety in the context of what feels achievable to the individual. The response to treatment is an individual matter and therefore people should be offered more than one evidence-based treatment and any available appropriate alternatives, which may include innovative interventions, if coherent expertise is available. In addition, neuropsychological development continues for many years into adulthood, so treatments can be tried again in the context of greater maturity.

A fluid approach to intervention may be taken, where people move in and out of periods of active treatment, (which could also include adapting goals).[183] At times it may be important to recognise that the eating disorder has taken the form of a chronic disability, at least in the medium term. At any stage it could be appropriate to discuss whether symptom-focused treatment has exhausted the energies of both patient and clinician, and the approach may be changed to a broader focus as either a temporary or a longer-term option (which may be less intensive). The door for recovery should always be left open so the individual has the opportunity to change their mind, re-engage and discuss options with an appropriately-trained healthcare professional (which may start with primary care).

However, it is likely that relentless imposition of therapeutic tasks (either with a symptom or broader focus) is only acceptable in a context of healthy change. Keeping people attached to services without measurable benefit might stand in the way of normal social supports and life skills. In such situations patients should be offered the opportunity to reduce the intensity of clinical input. In some cases this may become a long-term situation. The Mental Welfare Commission for Scotland and Central Legal Office involvement can be considered to support treatment decisions at any stage of their care and second opinions can be sought.

A very small number of patients may request that even potentially life-saving treatment should not be imposed upon them on a repeated, compulsory basis. This is an emotionally distressing situation and requires at least one formal second opinion and medico-legal involvement *(see section 3.4)*. Where it has been fully agreed and documented that the patient has the capacity to take such a decision, ongoing support should be offered to individuals, their families and other carers, including after death. However, there is a lack of evidence to guide the provision of such care.

R **Where active symptom-focused treatments have been exhausted either temporarily or in the medium-to-long term healthcare professionals may consider offering either adapted CBT-AN or adapted SSCM whilst monitoring risk and quality-of-life outcomes.**

✓ When it has been agreed that symptom-challenging treatment should stop quality-of-life treatment should be continued and support offered to the patient's family and other carers. This should be supported by robust ongoing clinical reviews.

✓ Patients who have disengaged from therapy should have the opportunity to change their mind, re-engage and discuss the options with an appropriately-trained healthcare professional.

ⓘ Individuals should be signposted to support from social services and to information about housing, education and employment rights. Further information on peer support groups, and support for family and carers is in section 16.2.

14 Pregnancy and postnatal care

14.1 Eating disorders during pregnancy and the postnatal period

Prevalence rates for eating disorders in pregnant women have been reported as 0.09% for anorexia, 0.94% for bulimia nervosa, 5% for binge eating disorder, and 0.1% for related disorders.[188] Screening of women attending antenatal clinics and postnatal follow up highlighted that disordered eating behaviour (assessed using the EDE-Q) during, and particularly after, pregnancy may be more common than expected, with 5.3% of prepartum and 12.8% of postpartum mothers screening positive.[189] — 2+

Systematic reviews assessing the impact of maternal eating disorders on dietary intake and eating patterns during pregnancy found that pregnancy is associated with overall improvements in eating behaviours in most women.[190,191] — 2⁻ 2++

A small study found that amongst women with current or past eating disorders, increased levels of eating disorder symptoms were present during pregnancy (compared with controls) in the first and second trimesters, although overall the severity of these symptoms reduced during the course of the pregnancy.[192] For women with current and past eating disorders, eating disorder symptoms increased again at 8 weeks and remained higher than controls at both 8 weeks and 6 months in the postnatal period.[192] — 2+

A further small study found that pregnancy was associated with an increase in body weight dissatisfaction in women with and without an eating disorder. Postpartum, women with a history of eating disorder tend to experience a rapid decrease in BMI. Their body weight dissatisfaction reduces to prepregnancy levels by 3 months.[193] — 2⁻

Qualitative research on the experiences of women with eating disorders during pregnancy has identified a number of themes relating to barriers to disclosure of eating disorders by women during pregnancy. These included stigma, lack of opportunity (limited enquiry by professionals), preference for self management, improvement in eating disorder symptomatology during pregnancy, their level of knowledge about their eating disorder and acknowledgement of their symptoms.[194] — JBI 3/11 Moderate

Key themes that emerged from interviews during pregnancy included navigating a 'new' eating disorder, with pregnancy representing a time of 'tumultuous' change with a 'battle between managing the eating disorder, the needs of the unborn child and feelings of loss of control'. Pregnancy was also perceived as a new context to view the body with considerations of the safety of the child and 'making space' for the baby. Women described 'hiding' the eating disorder and a return to the 'old' eating disorder with an overwhelming desire to lose weight.[195,196] Pregnancy was identified as a time of positive change in eating habits, more acceptance of their body and with the desire to meet the needs of the unborn child being greater than the eating disorder.[195] — JBI 9/11

The postpartum period was experienced by some women as a period of increased distress with themes relating to the loss of the prepregnancy body and equally loss of pregnancy identity, with increased drivers to lose weight.[196] — JBI 9/11

Findings from interviews with women also indicated that the pressure to relinquish the eating disorder identity, motivation and drive for change may be greater during a woman's first pregnancy compared to experiences with subsequent pregnancies.[196] — JBI 9/11

R **During pregnancy and the postnatal period healthcare professionals should routinely sensitively enquire if the woman has a current or past history of eating disorder and be aware of potential barriers for disclosure.**

R **Healthcare professionals should discuss with women who are pregnant how their eating disorder symptoms may change during the antenatal and postnatal period.**

R **Healthcare professionals should be aware of the risk of relapse, particularly in the postnatal period.**

✓ Referral to eating disorder services and/or perinatal mental health services should be considered for pregnant women with a current or past eating disorder.

✓ Care planning with the extended multidisciplinary team (eg maternity staff, eating disorder service, perinatal mental health services, general practitioner, health visitor, family nurse partnership or other agencies if relevant such as children's services) should be considered for pregnant women with a current or past history of an eating disorder relevant to their presenting needs.

14.2 Comorbid anxiety and depression

A systematic review found strong evidence for an association between eating disorder symptoms and depression and anxiety symptoms during pregnancy.[197] Additionally it found some evidence for an association between eating disorder symptoms and obsessive compulsive symptoms during pregnancy and between eating disorder symptoms and depressive symptoms during the postpartum period.[197] 2⁻

A large longitudinal study and a smaller study both found that at all time points during pregnancy and the postnatal period, women with an eating disorder have been found to experience higher rates of depressive symptoms than control groups during these periods.[192,198] 2⁺ 2⁺⁺

The smaller study also found that women who have an eating disorder are at increased risk of experiencing anxiety symptoms during pregnancy and postnatally.[192] 2⁺

R **Healthcare professionals providing care for women with a current or past eating disorder should consider assessing for depression and anxiety and offer evidence-based treatment as appropriate, alongside management of the eating disorder.**

Further guidance on perinatal mood disorders can be found in SIGN 127: Management of perinatal mood disorders.[199]

14.3 Medication use

Women with an eating disorder are more likely than women without an eating disorder to use psychotropic medication, gastrointestinal medication, such as laxatives, and analgesia during pregnancy.[188] Women with AN were found to be more likely to use sedative or anxiolytic medication in the postnatal period (0–6 months postpartum).[188] Women with BN or BED were more likely to use gastrointestinal medication during pregnancy compared to women without an eating disorder.[188] 2⁺

✓ All women of childbearing age should be given appropriate counselling on the balance of risks of untreated illness and of medication exposure during the different stages of pregnancy and postnatal period, taking into account breastfeeding. If possible discussions should start before conception.

14.4 Dietary intake

A systematic review, and two cohort studies found that women with a history of AN showed a significantly increased risk of iron deficiency anaemia during pregnancy.[190,200,201] 2⁻ 2⁺⁺ 2⁺

In general pregnant women with a history of an eating disorder achieve an adequate diet during pregnancy.[190] Women with lifetime AN or BN had similar patterns of nutrient intake and dietary supplements use as women without an eating disorder. 2⁻

Women with BED showed higher energy and fat intake during pregnancy.[190] 2⁻

Before and during pregnancy women with BED had a lower intake of folate, potassium and vitamin C, with a lower intake of fruit and juices during the second trimester.[190] 2⁻

R **Healthcare professionals should consider enhanced screening for iron deficiency anaemia for pregnant women who have a history of anorexia nervosa.**

✓ Healthcare professionals should undertake an approximate assessment of the nutritional intake of a pregnant woman with a current or history of an eating disorder, taking into account prepregnancy BMI and, if possible, gestational weight gain. Should there be concerns about the patient's nutritional intake (either low or high), specialist eating disorder dietetic assessment, intervention and weight monitoring should be considered. Other appropriate multidisciplinary interventions (including support to manage any distress secondary to the eating disorder) should be provided if indicated.

✓ Healthcare professionals should be aware that cultural practices or pregnancy diets in minority ethnic communities may mask eating disorders.

14.5 Obstetric outcomes

A systematic review and meta-analysis found that infants of mothers with AN are at increased risk of being low birth weight.[202] Large population study found that women with a lifetime history of AN were at higher risk of having infants who are small for gestational age, compared with controls.[203] Lifetime history of BN posed a higher risk of needing a caesarean section. The babies of women who had a subthreshold eating disorder had a higher likelihood of having a low Apgar score.[203] 2⁻ 2⁺

A large cohort study found that women with any eating disorder were found to be at higher risk of preterm birth and having babies with microcephaly.[201] Women with anorexia nervosa were at increased risk of antepartum haemorrhage.[201] A further cohort study found that lifetime AN and BN were associated with restricted foetal growth and increased risk of the baby being small for gestational age. Active AN in the mother was associated with increased risk of the baby being small for gestational age and of preterm labour.[204] 2⁺

Anorexia nervosa prior to pregnancy was associated with smaller birth length, BN with induced labour, and BED with larger birth length and large for gestational age.[205] Body mass index before pregnancy and weight gain during pregnancy may be important factors that influence these outcomes.[205] 3

R **Healthcare professionals should be aware that women with eating disorders may be at higher risk of obstetric complications.**

✓ Women with eating disorders or a history of eating disorders with a low or high prepregnancy BMI or failure to gain gestational weight, may be considered for additional obstetric monitoring during pregnancy (such as foetal growth scans) to support and allow multidisciplinary intervention if indicated.

✓ Healthcare professionals may wish to consider offering preconceptual advice regarding optimising nutritional status and promoting recovery to women with eating disorders, where possible, prior to conception.

14.6 Infant outcomes

A systematic review found that children (age 0–12 years) of mothers with an eating disorder are at increased risk of difficulties in feeding and eating behaviours and higher rates of social and emotional difficulties.[206] 2++

A small study of women with either a past or current eating disorder reported higher concerns about their infant being, or becoming overweight compared with other mothers. They also had less awareness of hunger and satiety cues.[207] 2+

One small case-control study reported some associations with neurobehavioural dysregulation after the birth of infants born to mothers with a history of, or a current, eating disorder. Infants of mothers with a current eating disorder were found to have higher autonomic instability at eight day's postpartum using the Neonatal Brazelton Assessment Scale. Infants of mothers with a history of eating disorder had poorer language and motor development at 1 year compared with other infants.[208] 2+

✓ Healthcare professionals should consider that infants of women with eating disorders (and their caregivers) may benefit from additional support with feeding, eating, social and emotional difficulties and should consider working collaboratively with health visiting staff and other parenting supports available locally.

14.7 Training and education

Healthcare professionals identified the following barriers to providing eating disorders support in the perinatal period: system constraints, role recognition (not seeing it as their role), personal attitudes, and the stigma and taboo of discussing eating disorders with pregnant and postnatal women. Lack of evidence-based knowledge and training impacted on confidence in discussing eating disorders. Other system constraints were poor continuity of care, poor communication between professionals and women and between healthcare professionals.[194] Another study highlighted the need to raise awareness and implement educational programmes and training of frontline healthcare staff.[189] JBI 3/11 2−

✓ Healthcare professionals working with pregnant and postnatal women should have training, relevant to their role, in identifying and appropriately managing patients with eating disorders.

15 Needs of diverse communities

The majority of research into eating disorders has been conducted in young white female populations. However, given the high prevalence of eating disorders in people who are on the autistic spectrum, such research may not actively be unduly biased towards neurotypical populations. Given the difficulties of undertaking any meaningful research in the field it is understandable that evidence is collected from the most convenient samples. There is a risk that services are then unable to offer appropriate treatments to those who do not match the populations studied. No good-quality quantitative evidence was identified to guide the treatment of male patients, ethnically diverse groups and people with LGBTQ+ identities. Much of the qualitative evidence highlights obstacles and difficulties to accessing treatment rather than providing outcomes for treatment.

Further research is required not only in each of these areas, but also to address more general questions around identification of eating disorders in diverse populations. There are a number of legal and policy frameworks which highlight that services have a duty to ensure that the diversity of people in Scotland have equitable access to good-quality care and treatment.[209-211] Annex 2 summarises guidance for services in further detail.

15.1 Men with eating disorders

A systematic review concluded that few studies with sufficient numbers of male participants exist so treatment outcomes for males were inconclusive.[212] Men with an eating disorder are less likely to receive treatment than women, although inpatient treatment is equally effective in males and females.[213,214] A small study that found that men had lower drive for thinness, and less body dissatisfaction than women.[215] In a single inpatient study mortality in male patients with eating disorders was found to be relatively higher than in females.[216]

3
2++
2⁻

Two systematic reviews of a total of ten qualitative studies compared treatment between men and women with an eating disorder.[217,218] Some of the key themes did not differ from those raised by female patients and within these studies participants expressed a range of differing views about the relevance of gender in treatment. The following key themes emerged:

- recognition of the eating disorder (delayed recognition, perception that it is a woman's illness, not fitting sociocultural perceptions)
- different clinical features in males (different body image concerns, and suppression of sexual function)
- longer delays in seeking treatment (shame/stigma, ambivalence toward the disorder, lack of knowledge and fear of subsequent rejection)
- accessing help (difficulty accessing treatment services, minimisation/lack of knowledge of eating disorders in men)
- characteristics of services and treatments (feminised services and psychoeducation, being a minority in services, experiencing care as control, lack of a person-centred approach, availability of tailored treatments).

JBI
7/10

15.2 LGBTQ+ people with eating disorders

Very little research, quantitative or qualitative, was identified on the specific needs of people with LGBTQ+ identities to support them with treatment for an eating disorder. Very little evidence was identified to provide specific guidance on any modifications to treatment for eating disorders that would be helpful when the person identifies as lesbian, gay or bisexual.

A metasynthesis of nine qualitative studies on the role of gender in treatment experiences of people with eating disorders found that there was a lack of understanding about gender issues among healthcare professionals treating people with eating disorders. Failure to acknowledge or address gender identity made people who identified as transgender more likely to disengage from the treatment. There was also concern that the issues discussed, or perceived to be the main issues for people with eating disorders were focused around cis-gender women and did not address the main concerns for men or transgender people.[219] The authors recommended that healthcare professionals address their own unconscious biases about transgender people. JBI 9/11

A survey of people identifying as transgender found that eating disorders decreased after gender-confirming medical interventions improved body satisfaction.[220] 3

15.3 Eating disorders in people from minority ethnic groups

Studies have reported high prevalence of eating disorders but low referral rates among people from minority ethnic groups, but research is needed to guide management and improve access to services *(see section 18.2)*.[7-9]

15.4 Recommendations

R **Sex differences and issues relating to gender identity should be sensitively considered by all healthcare professionals treating people with eating disorders.**

R **Teaching and training should be offered to all healthcare professionals to allow them to identify individuals with eating disorders, recognise potential variations in their profile of symptoms, and how diverse needs may impact treatment.**

R **Services should be designed so that all patients have equity of access to eating disorders services at all levels.**

R **Delivery of tailor-made, individualised care plans should accommodate considerations of diversity.**

✓ Where treatment services are specifically designed for the needs of a female-dominant group (particularly inpatient services) alternative services may be considered where there are mixed or more diverse communities.

✓ Where male patients have to be treated within a female-dominated group alternative services may be considered where there are mixed or all-male communities. No patient should be deprived of a service because it is dominated by a majority group.

✓ Where individuals are receiving treatment in specialist gender identity services, consideration of joint working and training between these services and eating disorder services may be of benefit.

✓ Services should encourage staff diversity in terms of age, gender and ethnicity to provide a welcoming environment for every patient.

16 Provision of information

This section reflects the issues likely to be of most concern to patients and their carers. These points are provided for use by healthcare professionals when discussing eating disorders with patients and carers and in guiding the development of locally-produced information materials.

16.1 Publications from SIGN

SIGN patient versions of guidelines are documents that 'translate' guideline recommendations and their rationales, originally developed for healthcare professionals, into a form that is more easily understood and used by patients and the public. They are intended to:

- help patients and carers understand what the latest evidence supports around diagnosis, treatment and self care
- empower patients to participate fully in decisions around management of their condition in discussion with healthcare professionals
- highlight for patients where there are areas of uncertainty.

A copy of the patient version of this guideline is available from www.sign.ac.uk/patient-publications

Other relevant SIGN patient booklets include:

- autism www.sign.ac.uk/patient-and-public-involvement/patient-publications/autism
- diabetes www.sign.ac.uk/patient-and-public-involvement/patient-publications/diabetes
- mood disorders during and after the birth of your baby www.sign.ac.uk/patient-and-public-involvement/patient-publications/mood-disorders-during-pregnancy-and-after-the-birth-of-your-baby

16.2 Sources of further information

Beat
Helpline: 0808 801 0677
Email: Scotlandhelp@beateatingdisorders.org.uk
www.beateatingdisorders.org.uk

Beat is a national charity that provides support for people with eating disorders, their family and friends. They also campaign to raise awareness and improve knowledge of eating disorders among healthcare professionals.

CARED Scotland
www.caredscotland.co.uk

CARED is a website providing information and resources for young people with eating disorders, their family and carers.

F.E.A.S.T.
www.feast-ed.org

F.E.A.S.T (Families Empowered And Supporting Treatment for Eating Disorders) is a global organisation which provides information and support to parents and carers of people with eating disorders.

MaleVoicED
www.Malevoiced.com

MaleVoicED provides a platform for all males, their caregivers, friends and associates to share narrative around their experience of poor relationships with food and comorbid conditions, with the aim that the sharing of narratives will improve services for males. The site also provides links to peer support groups, helplines and further information.

Mental Welfare Commission
Adviceline for personal queries: 0800 309 6809
Adviceline for professional queries: 0131 313 8777
Email: mwc.enquiries@nhs.scot
www.mwcscot.org.uk

The Mental Welfare Comission provides advice on rights and good practice in mental health and incapacity law, and care and treatment of people with mental health conditions.

NHSInform
Tel: 0800 22 44 88
www.nhsinform.scot

This is the national health and care information service for Scotland. It includes information and links to resources and to support people with eating disorders www.nhsinform.scot/illnesses-and-conditions/mental-health/eating-disorders

PEACE pathway
www.peacepathway.org

PEACE is a pathway for people with eating disorders and autism, developed from clinical experience, to support autistic people an eating disorder, their loved ones and their clinicians.

Scottish Association for Mental Health (SAMH)
Tel: 0344 800 0550
www.samh.org.uk

SAMH promotes national mental health campaigns and work with adults and young people to provide mental health support. They provide an information service on mental health problems, self help and wellbeing, and support for carers.

16.3 Checklist for provision of information

This section gives examples of the information patients/carers may find helpful at the key stages of the patient journey. The checklist was designed by members of the guideline development group based on their experience and their understanding of the evidence base. The checklist is neither exhaustive nor exclusive.

Initial Intervention

- Signposting and information on further support should be provided as early as possible.
- Acknowledge the difficulty in asking for help and reassure that ambivalence about recovery and seeking treatment is normal.
- Discuss reasons for seeking help, ensuring that emotional state and wellbeing is recognised beyond just physical symptoms.
- People with eating disorders may think they must become more unwell before they deserve help, or they are allowed to recover. Provide reassurance that there is no such thing as unwell enough and that they do deserve to get well.
- Explain the diagnosis, if made, and discuss treatment options. Include signposting to community, social and interim support such as Beat *(see section 16.2)*.
- Emphasise the need for hope, that no matter how long someone has struggled with an eating disorder and how bleak they may feel about their future, and that things can change for them, their carers, family, etc.

Supporting someone through treatment

- Discuss treatment plans with patients and allow them to share their ideas and concerns. Explain how a therapy works and why it may be appropriate for that individual.
- Pregnancy: encourage anyone who has, or has a history of, an eating disorder and is planning a pregnancy, to discuss their eating disorder so support can be arranged.
- Always be mindful of the individual needs of patients, in terms of, for example gender identity, access issues, ethnicity, age, beliefs and language.
- Encourage the individual to build a supportive network which may involve family and/or friends, while respecting the individual's right to confidentiality *(see section 3.2)*.
- Engage in discussions about returning to activities stopped during treatment, eg exercise. Life after treatment, and life after an eating disorder, should be considered.
- Ensure the patient knows how to access support programmes, when needed, as they continue through their recovery journey *(see section 16.2)*.

17 Implementing the guideline

This section provides advice on the resource implications associated with implementing the key clinical recommendations, and advice on audit as a tool to aid implementation.

17.1 Implementation strategy

Implementation of national clinical guidelines is the responsibility of each NHS board, including health and social care partnerships, and is an essential part of clinical governance. Mechanisms should be in place to review care provided against the guideline recommendations. The reasons for any differences should be assessed and addressed where appropriate. Local arrangements should then be made to implement the national guideline in individual hospitals, units and practices.

Implementation of this guideline will be encouraged and supported by SIGN. The implementation strategy for this guideline encompasses the following tools and activities.

17.2 Resource implications of key recommendations

No recommendations are considered likely to reach the £5 million threshold which warrants resource impact analysis.

17.3 Auditing current practice

A first step in implementing a clinical practice guideline is to gain an understanding of current clinical practice. Audit tools designed around guideline recommendations can assist in this process. Audit tools should be comprehensive but not time consuming to use. Successful implementation and audit of guideline recommendations requires good communication between staff and multidisciplinary team working.

The guideline development group has identified the following as key points to audit to assist with the implementation of this guideline:

- Collect appropriate, nationally-agreed baseline and outcome data on all patients.
- Collect specific data on the uptake of services by minority ethnic groups, men and people of different gender identities.
- Any Scottish NHS boards that implement the FREED model will automatically be included in the FREED research group and should contribute to data collection and further evaluation of the model.
- When using therapies with only preliminary evidence, collect baseline and outcome data to determine efficacy.
- Collect prescribing data in adults with AN.
- Collect data on training provided to staff on EDs.
- Research whether services can provide the recommended psychological therapies and associated accredited training and supervision requirements.

18 The evidence base

18.1 Systematic literature review

The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Evidence and Information Scientist. Databases searched include Medline, Embase, Cinahl, PsycINFO and the Cochrane Library. The year range covered was 2009-2020. Internet searches were carried out on various websites for relevant guidelines. The main searches were supplemented by material identified by individual members of the development group. Each of the selected papers was evaluated by two Evidence and Information Scientists using standard SIGN methodological checklists before conclusions were considered as evidence by the guideline development group

The search strategies are available on the SIGN website, www.sign.ac.uk

18.1.1 Literature search for qualitative studies

A SIGN Evidence and Information Scientist conducted a literature search of Medline, Embase and Psychinfo, using a standard qualitative search filter, up to 2019. The studies were appraised and summarised by a qualitative researcher from The Scottish Joanna Briggs Institute (JBI) Centre of Excellence. Qualitative studies were graded using the 10-item JBI checklist for qualitative research. It was decided a priori that studies scoring 8–10 (out of 10) would be considered high quality, 5–7 (out of 10) moderate quality, and 4 or below low quality. Qualitative syntheses were graded using the 11-item JBI checklist for systematic reviews and research syntheses. It was decided a priori that studies scoring 9–11 (out of 11) would be considered high quality, 5–8 moderate quality, and 4 or below low quality jbi.global/critical-appraisal-tools.

18.1.2 Literature search for patient issues

At the start of the guideline development process, a SIGN Evidence and Information Scientist conducted a literature search for qualitative and quantitative studies that addressed patient issues of relevance to management of patients with an eating disorder. Databases searched include Medline, Embase, Cinahl and PsycINFO, and the results were summarised by the SIGN Patient Involvement Advisor and presented to the guideline development group.

18.1.3 Literature search for cost-effectiveness evidence

The guideline development group identified key questions with potential cost-effectiveness implications, based on the following criteria, where it was judged particularly important to gain an understanding of the additional costs and benefits of different treatment strategies:

- treatments that may have a significant resource impact
- opportunities for significant disinvestment or resource release
- the potential need for significant service redesign
- cost-effectiveness evidence could aid implementation of a recommendation.

A systematic literature search for economic evidence for these questions was carried out by a SIGN Evidence and Information Scientist covering the years 2009-2020. Databases searched include Medline, Embase and NHS Economic Evaluation Database (NHS EED). Each of the selected papers was evaluated by a Health Economist, and considered for clinical relevance by guideline group members.

Interventions are considered to be cost effective if they fall below the commonly-accepted UK threshold of £20,000 per Quality-Adjusted Life Year (QALY).

18.2 Recommendations for research

There has been limited funding for eating disorder research, globally and in the UK, in comparison to other mental health presentations, and physical health conditions.[221,222] It has been reported that research funding for prevention, detection, the development of novel treatments and health service models in eating disorders was significantly lacking.[221]

It has been suggested that the marginalisation of eating disorders within the research community is a consequence of the stigma associated with eating disorders, for example the perception that these are transient and superficial difficulties associated with young women, perpetuating a perception that they are not as important or severe as other mental health conditions.[223] Prevalence rates and the costs associated with eating disorders in Europe have been severely underestimated due to the most common eating disorders, such as BED, not being recorded.[224] Both of these factors, and the associated marginalisation of eating disorder research, has potentially had an impact on the perceived need or urgency for research in the area by funders.

This has a direct consequence on the production of clinical guidelines. The guideline development group was not able to identify sufficient evidence to answer all of the key questions *(see Annex 1)*. There was an absence of robust RCTs in EDs other than AN, especially in children and adolescents, despite many initial presentations occurring within this age group. Little research was identified for eating disorders in men, people with LGBTQ+ identities, ethnic groups, autistic people and those experiencing more severe and prolonged presentations. Even where a number of RCTs were identified, attrition and relapse rates were high, highlighting the need for further evaluation and development of interventions.

There is an urgent need for robust, large scale, multicentre RCTs for eating disorders in the UK to enhance and refine existing treatment protocols and support the development of novel psychological and biological interventions. It is essential that moderators of treatment are considered to support our understanding of who benefits most from different treatment modalities, to support more effective treatment pathways. Research should be coproduced with patients, families and carers.

It is also important that there is a research and data-driven ethos within clinical services in Scotland. There is a need for agreement on standardised outcome measures and the implementation of an associated national data set across all eating disorder services. Along with robust quality improvement methodology, this will enable clinicians to work collaboratively across the country to support implementation of best practice and to improve service provision.

The following topics for further research have been identified:

- The nature, management and effective treatment of eating disorders in groups previously marginalised in existing research. This includes men, people with LGBTQ+ identities, autistic people, and individuals experiencing comorbidity (particularly type 1 diabetes, PTSD, OCD and substance use disorder). There is little research focusing the development, presentation and intervention approaches specific to eating disorders among minority ethnic groups and this needs to be prioritised.
- The development of novel psychological and biological interventions through robust, large scale, multisite RCTs. Presentations where there is a lack of robust RCTs, or where RCTs exist but there are high rates of remission and relapse, should be prioritised, eg ARFID across all ages, BED across all ages, BN in young people, and AN in adults.
- The benefits of input from physiotherapy, occupational therapy, art therapy and other interventions to provide a holistic approach to care.
- Long-term follow up studies required to look at outcomes for those in whom (a) exercise and (b) treatment of dysfunctional exercise and activity were included as part of eating disorder treatment, in community- and hospital-based settings.

- The definition, management and treatment of individuals with severe and enduring eating disorders, addressing quality of life as well as core eating disorder psychopathology.
- The incorporation of a holistic definition of recovery, rather than one focused on weight in isolation, and associated biological and psychological interventions that promote maintenance of recovery following active treatment.
- Clinical management of eating disorders during pregnancy and the perinatal period.
- Treatments for medical sequelae of eating disorders.
- Robust evaluation of healthcare models for eating disorders. This might include treatment provision (eg intensive treatment teams, stepped care models), methods of delivery (inclusive of digital technology), and pathways which reduce the length of untreated presentations and disruptive transitions.

18.3 Review and updating

This guideline was issued in 2022 and will be considered for review in 3 years. The review history, and any updates to the guideline in the interim period, will be noted in the update report, which is available in the supporting material section for this guideline on the SIGN website: www.sign.ac.uk

Comments on new evidence that would update this guideline are welcome and should be sent to the SIGN Executive, Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EB (email: sign@sign.ac.uk).

19 Development of the guideline

19.1 Introduction

SIGN is a collaborative network of clinicians, other healthcare professionals and patient organisations and is part of Healthcare Improvement Scotland. SIGN guidelines are developed by multidisciplinary groups of practising healthcare professionals using a standard methodology based on a systematic review of the evidence. Further details about SIGN and the guideline development methodology are contained in 'SIGN 50: A Guideline Developer's Handbook', available at www.sign.ac.uk

This guideline was developed according to the 2019 edition of SIGN 50.

19.2 The Guideline Development Group

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Dr Stephen Anderson	Consultant Psychiatrist, Adult Eating Disorder Service, NHS Greater Glasgow and Clyde
Dr Jenny Bennison	General Practitioner, Niddrie Medical Practice, Edinburgh
Professor Kay Cooper	Director of the Scottish Joanna Briggs Centre of Excellence, Robert Gordon University, Aberdeen
Mr Brian Dawson	Specialist Nurse, Tayside Eating Disorder Service
Dr Fiona Duffy	Consultant Clinical Psychologist, CAMHS, NHS Lothian
Ms Hazel Elliott	Specialist Eating Disorder Dietitian, St John's Hospital, Livingston
Dr Selena Gleadow-Ware	Consultant Perinatal Psychiatrist, St Johns Hospital, Livingston
Dr Ann Gold	Consultant Diabetologist, Aberdeen Royal Infirmary
Dr Heather Ireland	Consultant Psychiatrist, New Craigs Hospital, Inverness
Ms Ellen Maloney	Patient representative and BEAT Ambassador, Edinburgh
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Dr Karen McMahon	Family Based Treatment Therapist and Lecturer, University of West Scotland, Glasgow
Dr Katherine Morton	Consultant Psychiatrist, NHS Lanarkshire
Dr Charlotte Nevison	Consultant Clinical Psychologist, NHS Greater Glasgow and Clyde
Ms Charlotte Oakley	Dietician and Clinical Lead Connect-Eating Disorders Specialist Children's Services, NHS Greater Glasgow and Clyde
Dr Joy Olver	Consultant Child and Adolescent Psychiatrist, North of Scotland CAMHS Tier 4 Network, Young People's Unit, Dundee
Ms Sandra Phillip Rafferty	Highly Specialist Physiotherapist, Royal Cornhill Hospital, Aberdeen
Dr Susan Simpson	Consultant Clinical Psychologist, St John's Hospital, Livingston
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Dr Rachael Smith	Consultant Clinical Psychologist and Professional Lead for CAMHS, NHS Grampian
Ms Ailsa Stein	Programme Manager, SIGN Executive, Edinburgh

Ms Pamela Thorn	Highly Specialist Clinical Pharmacist, Royal Cornhill Hospital, Aberdeen
Mrs Anne Tremble	Carer representative, Glenrothes
Dr Joanne Waine	Consultant Clinical Psychologist, NHS Lanarkshire

The membership of the guideline development group was confirmed following consultation with the member organisations of SIGN. All members of the guideline development group made declarations of interest. A register of interests is available in the supporting material section for this guideline at www.sign.ac.uk

Guideline development and literature review expertise, support and facilitation were provided by SIGN Executive and Healthcare Improvement Scotland staff. All members of the SIGN Executive make yearly declarations of interest. A register of interests is available on the contacts page of the SIGN website www.sign.ac.uk

Kirsty Littleallan	Project Officer
Juliet Brown	Evidence and Information Scientist
Kelly Humphrey	Project Officer
Karen Graham	Patient and Public Involvement Advisor
Gaynor Rattray	Guideline Co-ordinator
Domenico Romano	Publications Designer

19.3 Consultation and peer review

A report of the consultation and peer review comments and responses is available in the supporting material section for this guideline on the SIGN website. All expert referees and other contributors made declarations of interest.

19.3.1 National open meeting

A national open meeting is the main consultative phase of SIGN guideline development, at which the guideline development group presents its draft recommendations for the first time. The national open meeting for this guideline was held on 26 May 2021 and was attended by 176 representatives of all the key specialties relevant to the guideline. The draft guideline was also available on the SIGN website for a limited period at this stage to allow those unable to attend the meeting to contribute to the development of the guideline.

19.3.2 Specialist review

This guideline was also reviewed in draft form by the following independent expert referees, who were asked to comment primarily on the comprehensiveness and accuracy of interpretation of the evidence base supporting the recommendations in the guideline. The guideline group addresses every comment made by an external reviewer, and must justify any disagreement with the reviewers' comments.

SIGN is very grateful to all of these experts for their contribution to the guideline.

Dr Gail Allsopp	Clinical Policy Lead, Royal College of General Practitioners, London
Dr Subhayu Bandyopadhyay	Consultant Obstetrician, Aberdeen Maternity Hospital
Dr Heike Bartel	Associate Professor in German School of Cultures, Languages and Area Studies, University of Nottingham

Ms Emma Broadhurst	National Officer Scotland, Beat
Ms Kate Brown	Physiotherapy Lead (Mental Health), Cambridge and Peterborough NHS Foundation Trust
Dr Donna Corrigan	Carer and Consultant Paediatrician, University Hospital Wishaw
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Dr Andrew Gallagher	Consultant Physician and Endocrinologist, Queen Elizabeth University Hospital, Glasgow
Ms Sara Gemmell	Carer/lay representative, Falkirk
Dr Shridevi Gopi-Firth	Speciality Doctor in Eating Disorders, NHS Forth Valley
Ms Alison Hall	Autism Nurse Specialist, NHS Forth Valley
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Miss Jennifer McNeil	Patient representative, Glasgow
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Ms Lorraine Small	Community Psychiatric Nurse, CAMHS, Royal Edinburgh Hospital
Mrs Debbie Smith	Specialist Occupational Therapist, Regional Eating Disorder Unit, Livingston
Dr Richard Taylor	Consultant Psychiatrist, Regional Eating Disorder Unit, Livingston
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Dr Wojtek Wojcik	Consultant Psychiatrist and Clinical Director for Specialist Services (Mental Health), Royal Infirmary of Edinburgh

19.3.3 Acknowledgements

SIGN would like to acknowledge the additional expert advice provided by the Mental Welfare Commission for Scotland.

Dr Arun Chopra	Executive Director (Medical), Mental Welfare Commission for Scotland
Ms Alison Thomson	Executive Director (Nursing), Mental Welfare Commission for Scotland

19.3.4 SIGN editorial group

As a final quality control check, the guideline is reviewed by an editorial group comprising the relevant specialty representatives on SIGN Council to ensure that the specialist reviewers' comments have been addressed adequately and that any risk of bias in the guideline development process as a whole has been minimised. The editorial group for this guideline was as follows. All members of SIGN Council make yearly declarations of interest. A register of interests is available on the SIGN Council Membership page of the SIGN website www.sign.ac.uk

Dr Roberta James	SIGN Programme Lead; Co-Editor
Dr Ahmed Khan	Royal College of Psychiatrists
Dr Safia Qureshi	Director of Evidence, Healthcare Improvement Scotland
Dr David Stephens	Royal College of General Practitioners
Professor Angela Timoney	Chair of SIGN; Co-Editor
Professor David Wilson	Royal College of Paediatrics and Child Health

Abbreviations

ACT	acceptance and commitment therapy
AFT	adolescent focused therapy
AN	anorexia nervosa
ANTOP	Anorexia Nervosa Treatment of OutPatients
ARFID	avoidant/restrictive food intake disorder
ASD	autism spectrum disorder
BED	binge eating disorder
BES	binge eating scale
BMD	bone mineral density
BMI	body mass index
BN	bulimia nervosa
BPD	borderline personality disorder
BST	brief strategic therapy
CAMHS	child and adolescent mental health service
CAT	cognitive analytical therapy
CBT	cognitive behavioural therapy
CBT-A	cognitive behavioural therapy adapted for adolescents
CBT-AN	cognitive behavioural therapy adapted for anorexia nervosa
CBT-BN	cognitive behavioural therapy adapted for bulimia nervosa
CBT-E	enhanced cognitive behavioural therapy for eating disorders
CFT	compassion-focused therapy
cGSH	guided self-help cognitive behavioural therapy
CHIME	connectedness, hope and optimism, identity, meaning & purpose and empowerment
CI	confidence interval
CrI	credible interval
CRT	cognitive remediation therapy
DBT	dialectical behavior therapy
DEPS-R	diabetes eating problems survey revised
DERS	difficulties in emotion regulation scale
DHEA	dehydroepiandrosterone
DKA	diabetic ketoacidosis
DSM	Diagnostic and Statistical Manual of Mental Disorders
DXM	dual-energy X-ray absorptiometry
ECG	electrocardiogram

ECHO	Expert Carers Helping Others
ECHR	European Convention on Human Rights
EDE	eating disorder examination
EDE-Q	eating disorder examination questionnaire
EDI	eating disorder inventory
EDNOS	eating disorder not otherwise specified
EE	Expressed Emotion
ESM	emotional and social mind training
FBT	family-based treatment
FBT-BN	family-based treatment adapted for bulimia nervosa
FPT	focal psychodynamic therapy
FREED	First Episode and Rapid Early intervention in Eating Disorders
GMC	General Medical Council
GP	general practitioner
GPIP	group psychodynamic interpersonal psychotherapy
HbA1c	glycated haemoglobin
HEB	healthy exercise behaviour
ICAT	integrative cognitive-affective therapy
ICD	International Classification of Diseases
IPT	interpersonal psychotherapy
IPT-BN	interpersonal psychotherapy – bulimia nervosa
JBI	Joanna Briggs Institute
LEAP	Loughborough exercise and activity programme
LGBTQ+	lesbian, gay, bisexual, transgender, queer, or non-binary
LDX	lisdexamfetamine
MA	marketing authorisation
MANTRA	Maudsley Model of Anorexia Treatment for Adults
MAOI	monoamine oxidase inhibitors
MBT	mentalisation-based therapy
MBT-ED	mentalisation-based therapy – eating disorders
MEED	Medical Emergencies in Eating Disorders
MFT	multifamily therapy
MWC	Mental Welfare Commission
NICE	National Institute for Health and Care Excellence
OAO	Overcoming Anorexia Online
OCD	obsessive-compulsive disorder

OR	odds ratio
PD	personality disorder
PDT	psychodynamic therapy
PEACE	Pathway for Eating disorders and Autism developed from Clinical Experience
PTSD	post-traumatic stress disorder
RCT	randomised controlled trial
RED-S	relative energy deficiency in sport
RO DBT	radically open dialectical behavior therapy
RR	relative risk
SEDIG	Scottish Eating Disorders Interest Group
SE-ED	severe and enduring eating disorder
SEES	Safe Exercise at Every Stage
SIDMA	significantly impaired decision-making ability
SIGN	Scottish Intercollegiate Guidelines Network
SPT	supportive psychotherapy
SSCM	specialist supportive clinical management
SSCM-ED	specialist supportive clinical management – eating disorders
SSRI	selective serotonin reuptake inhibitor
SyFmTx	systemic family therapy
TAU	treatment as usual
TCA	tricyclic antidepressant
WLC	waiting-list controls

Annex 1

Key questions addressed in this update

This guideline is based on a series of structured key questions that define the target population, the intervention, diagnostic test, or exposure under investigation, the comparison(s) used and the outcomes used to measure efficacy, effectiveness, or risk. These questions form the basis of the systematic literature search.

Section	Key question
	In all key questions: Consider comorbidities: • personality disorder • complex trauma • autism spectrum disorder (ASD) • substance misuse • physical illness • obsessive-compulsive disorder (OCD) • depression • post-traumatic stress disorder (PTSD) • anxiety • bipolar affective disorder • schizophrenia Consider setting
5.1	1. What psychological therapies are effective in the treatment of children and adolescents with anorexia nervosa? Interventions: • family therapies • family-based treatment (FBT) • interpersonal therapy (IPT) • cognitive behavioural therapy (CBT) • enhanced cognitive behavioural therapy (CBT-E) • adolescent-focused therapy (AFT) • dialectical behavioural therapy (DBT) • cognitive analytical therapy (CAT) • acceptance and commitment therapy (ACT) • group therapy • individual therapy • Supportive Specialist Clinical Management (SSCM) • Schema therapy • Radically Open Dialectical Behaviour Therapy (RO DBT) • compassion-focused therapy (CFT) • cognitive remediation therapy (CRT) Comparators: • between therapies • treatment as usual • waiting-list control

	Outcomes: psychological Improvement (eg EDE, EDE-Q, EDI) quality-of-life measures (eg Clinical Global Outcomes (CGII)) return to normal activities weight improvement weight restoration BMI change (in relation to age and height)
6.1, 7.1	2. What psychological therapies are effective in the treatment of children and adolescents with bulimia nervosa or binge eating disorder? Interventions: • family therapies • family-based treatment (FBT) • interpersonal therapy (IPT) • cognitive behavioural therapy (CBT) • enhanced cognitive behavioural therapy (CBT-E, CBT-BN) • adolescent-focused therapy (AFT) • dialectical behavioural therapy (DBT) • cognitive analytical therapy (CAT) • acceptance and commitment therapy (ACT) • group therapy • individual therapy • Supportive Specialist Clinical Management (SSCM) • Schema therapy • Radically Open Dialectical Behaviour Therapy (RO-DBT) • compassion-focused therapy (CFT) • cognitive remediation therapy (CRT) • brief strategic therapy Comparators: see KQ1 Outcomes: • psychological Improvement (eg EDE, EDE-Q, EDI) • quality-of-life measures (eg CGII) • frequency of binge/purge behaviour • return to normal activities • relapse
8.1	3. What psychological therapies are effective in the treatment of children and adolescents with eating disorders and type 1 diabetes? Interventions: see KQ1 Comparators: see KQ1 Outcomes: • psychological Improvement (eg EDE, EDE-Q, EDI) • quality-of-life measures (eg CGII) • return to normal activities • insulin compliance (HbA1c levels) • improved scores in Diabetes Eating Problems Survey revised (DEPS-R) • general hospital admissions • diabetic ketoacidosis episodes

	• severe hypoglycaemia episodes • weight Improvement • weight restoration • BMI change (in relation to age and height) • relapse • remission (no longer meets diagnostic criteria) • cost effectiveness
1.2.1	4. What therapies are effective in the treatment of children and adolescents with avoidant/ restrictive food intake disorder (ARFID)? Interventions: • family-based treatment (FBT) • family therapy • adolescent-focused therapy (AFT) • cognitive behavioural therapy (CBT) • enhanced cognitive behavioural therapy (CBT-E) • parenting training/coaching • dietetics Comparators: • between therapies • treatment as usual • waiting list control Outcomes: • psychological improvement • quality-of-life measures (eg CGII) • return to normal functioning • nasogastric feeding rates • hospital admissions • BMI change (in relation to age and height) • relapse • remission (no longer meets diagnostic criteria) • cost effectiveness Consider comorbidities: • ASD • OCD • PTSD • physical comorbidities
9.1–9.4	5. What psychological therapies are effective in the treatment of adults with anorexia nervosa? Interventions: see KQ1 (not AFT), and: • mentalisation-based therapy (MBT) • focal psychodynamic therapy (FPT) • Maudsley Model of Anorexia Treatment for Adults (MANTRA) Comparators: see KQ1 Outcomes: see KQ1

10.1–10.3	6. What psychological therapies are effective in the treatment of adults with bulimia nervosa or binge eating disorder? Interventions: See KQ2 (not AFT), and: • mentalisation-based therapy (MBT) • psychodynamic therapy Comparators: see KQ2 Outcomes: see KQ2
8.1	7. What psychological therapies are effective in the treatment of adults with an eating disorder and type 1 diabetes? Interventions: see KQ1 (not AFT), and: • mentalisation-based therapy (MBT) • focal psychodynamic therapy (FPT) • Maudsley Model of Anorexia Treatment for Adults (MANTRA) Comparators: see KQ1 Outcomes: see KQ3
3.3	8. In patients with anorexia nervosa, which factors are associated with good maintenance of recovery? Population: Children, adolescents or adults with anorexia nervosa Interventions: • feeding to a healthy weight range • addressing compulsive exercise Outcomes: • stability of weight gain • psychological improvement (eg EDE, EDE-Q, EDI) • Clinical Global Outcomes • return to work/education • adverse events
5.2	9. In children and adolescents who have anorexia nervosa are pharmacological therapies effective in improving outcomes? Interventions: • antidepressants • antipsychotic drugs • other Comparators: • between pharmacological therapies • placebo • usual care Outcomes: • reduction in distress/anxiety • remission (no longer meets diagnostic criteria) • relapse • mortality • adverse effects • weight gain • cost effectiveness

6.2, 7.2	10. In children and adolescents who have bulimia nervosa or binge eating disorders are pharmacological therapies effective in improving outcomes? Interventions, comparators and outcomes: see KQ9
8.2	11. In children and adolescents who have an eating disorder and type 1 diabetes are pharmacological therapies effective in improving outcomes? Interventions and comparators: see KQ9 Outcomes: • reduction in distress/anxiety • relapse • remission (no longer meets diagnostic criteria) • mortality • insulin compliance (HbA1c levels) • improved scores in Diabetes Eating Problems Survey revised (DEPS-R) • general hospital admissions • diabetic ketoacidosis episodes • severe hypoglycaemia episodes • adverse effects • cost effectiveness
9.5	12. In adults who have anorexia nervosa are pharmacological therapies effective in improving outcomes? Interventions, comparators and outcomes: see KQ9
10.4	13. In adults who have bulimia nervosa or binge eating disorder are pharmacological therapies effective in improving outcomes? Interventions, comparators and outcomes: see KQ9
8.2	14. In adults who have an eating disorder and type 1 diabetes are pharmacological therapies effective in improving outcomes? Interventions and comparators: see KQ9 Outcomes: see KQ11
12	15. In patients who have anorexia, what is the best treatment to obtain optimal bone mineral density? Interventions: • renutrition to a healthy weight • bisphosphonates • hormone preparations (oestrogen) • calcium and vitamin D supplements • exercise programmes Comparators: • placebo • usual care Outcomes: • improved bone mineral density • reduced fracture risk (vertebral/hip/other) at 1, 5 and 10 years • adverse effects • treatment concordance • cost effectiveness

13	16. What treatment and continuing care is required by people with severe and enduring eating disorder (SE-ED) or treatment-resistant eating disorder? Interventions: • supportive psychotherapy • physical monitoring • dietetic advice • family support • occupational therapy • peer group support • modified CBT • SSCM • pharmacology • palliative care programmes Comparator: no treatment Outcomes: • quality of life • mood disorder symptoms • social adjustment • activities of daily living • weight change (BMI) • change in eating disorder pathology • improved motivation for change • reduction in hospital admissions
14	17. What are the most effective interventions to support pregnant women who have an eating disorder? Interventions: • high-risk monitoring/prebirth plans • antidepressants • antipsychotics • mother and baby unit admission • nasogastric feeding or nutritional support/supplements Comparator: treatment as usual Outcomes: • relapse • mood (depression/anxiety) • preterm labour • intrauterine growth retardation • neonatal adaptation syndrome • small for dates • large for dates • cost effectiveness
14	18. What are the most effective postnatal interventions to support new mothers who have an eating disorder? Interventions: • mother-infant interventions • CBT

	• IPT • parenting interventions • couple counselling • video interactive guidance • mentalisation • lamotrigine • antidepressants • antipsychotics Comparator: treatment as usual Outcomes: • relapse prevention • relapse • mood disorder • infant outcomes (growth and developmental ages and stages) • attachment • bonding • recovery from eating disorder • cost effectiveness
3.2	19. What interventions are effective in supporting parents, siblings and carers of people with eating disorders? Interventions: parent/carer training/coaching (eg Maudsley, Experienced Carers Helping Others (ECHO). Comparator: no intervention Outcomes: • reduction in anxiety/distress for parents/carers • improved quality of life for parents/carers • improved and sustained outcomes for patients with eating disorders
15.1, 15.3	20. a. What are the most effective interventions for people who identify as male who have an eating disorder? Interventions, comparators and outcomes: see KQs1–5, 16 b. What are the needs and preferences of people who identify as male when receiving treatment for an eating disorder? Phenomena of interest: the views opinions and experiences of boys and men on treatment for eating disorders
15.2, 15.3	21. a. What are the most effective interventions for lesbian, gay, bisexual, transgender or non-binary people who have an eating disorder? Interventions, comparators and outcomes: see KQs1–5, 16. b. What are the needs and preferences of lesbian, gay, bisexual, transgender or non-binary people when receiving treatment for an eating disorder? Phenomena of interest: the views opinions and experiences of people who are LGBT on treatment for an eating disorder.
3.1	22. In people with eating disorders does early intervention improve outcome? Intervention: early intervention models of care Comparator: usual care

	Outcome: • quicker, more sustained recovery • cost effectiveness
3.4	23. What are the risks and benefits of implementing the Mental Health Act for people with anorexia? Interventions: • application of the mental health act • involuntary treatment Comparators: • waiting for/counselling to gain consent • parental consent Outcomes: • patient acceptance • parent and carer acceptance • treatment outcomes
3.5	24. a. What are the main requirements for ensuring effective and safe transition between services for people with eating disorders? Population: People with eating disorders and their family/carers moving from • paediatric to adult services • changing health board area Intervention: models of transition Comparators: • between models • no structured transition Outcomes: • engagement with adult services/continuity of care • relapse rates • patient/family/carer satisfaction • cost effectiveness • adverse events b. What are the views and experiences of people with an eating disorder, their carers and healthcare providers on transition between services? Phenomena of interest: the process and experience of transition from paediatric to adult eating disorders services, or between services Context: • paediatric to adult services • changing health board area Outcomes: • improved engagement with healthcare services • improved patient/carer/family satisfaction
3.3.4	25. What follow up care is required to help people who have had treatment for an eating disorder to maintain their recovery? Outcomes: • quality of life • maintenance of a healthy weight • relapse

Annex 2

Improving the delivery of care to the diverse communities of Scotland

A number of legal and policy frameworks in Scotland emphasise that public services have a duty to ensure that all members of the diverse communities of Scotland have access to good-quality care and treatment.[209-211] There is a responsibility to ensure that inequalities in access to care, quality of care and barriers to care are addressed by services.

Provision of person-centred care that has an awareness of these issues and which enables adaptation of assessment, care and treatment to address the holistic needs and issues experienced by people seeking care can help reduce culturally inappropriate interventions, reduce disparities in care, build confidence in care, humanise and restore hope to people from diverse backgrounds who are at increased risk of disadvantage, discrimination and poorer health outcomes.[225]

This Annex highlights areas of recommendation relevant to the provision of eating disorder services in the documents cited, to ensure that services:

i. Gather service user information on protected characteristics as outlined by the Equality Act (2010) such as age, disability, race, religion or belief, sex, sexual orientation, gender reassignment, pregnancy and maternity status, marriage and civil partnership.[209] This could be done through approaches such as equality audits (Scottish National Equality Audit Improvement Project, Mainstreaming Equality, Making Progress, or NHS Scotland Equality and Diversity Impact Assessment Toolkit to ensure that services are meeting the needs of all communities.[226,227]

ii. Gather workforce data as required by the Equality Act 2010 (Specific Duties) (Scotland) Regulations (2012) and encourage positive steps to ensuring a representative and inclusive workforce, such as the UK Workplace Equality Index (Stonewall), diversity champion programmes, eg Stonewall Diversity Champions, or the Race at Work Charter, in keeping with the Scottish Government's Race Equality Framework (2016-2030) that aims to achieve race equality in Scotland.[209-211,228,229]

iii. Provide access to training, for example on cultural competency, multigenerational impacts of colour-based racism, intersectional discrimination and provision of antiracist mental healthcare.[211,225]

iv. Take action to overcome barriers to care such as use of language, stigma and discrimination.[230]

v. Provide specific measures such as access to interpreting services and adaptations to relevant therapeutic interventions including psychopharmacology and psychological therapies.[225]

vi. Address factors that weaken good practice and promote approaches that value diversity and discourage stereotyping.[210]

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978-1-909103-89-4

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