Eating disorders (update)

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ID	Stakeholder	Comment no.	Section no.	Comments	Developer's response
52	Alder Hey Children's NHSFT	1	General	My main comment is that people with an eating disorder linked to another medical condition will not be covered and in our hospital speciality practice most of our worst anorexic or bulimic patients have other conditions making the management doubly difficult. The reason for excluding them is not stated and seems to be a lost opportunity. Another important issue is the young adult age group of 18-25 where the vulnerabilities are greater and where patients are in the process of being transferred between paediatric and adult teams and where psychological comorbidities really worsen their chances of a good transition. The need for a separate focus on this age group and how they actually access age appropriate services is really important. E.g. we have currently a young a patient who has just turned 18 on the ward with severe weight loss in the setting of a previously treated inflammatory disease. Here the fears of the condition and treatment side effects have started the bulimia but where any suggestion of an eating disorder being the primary condition are resisted strongly and where the most expert dieticians and other eating disorder teams are challenged. This is the point about specialist as well as generalist expertise in the MDT care of these patients. Another example is a young person treated and cured of	Thank you for your comment. We acknowledge the concerns you raise and recognise the importance of these issues however the prime focus of the guideline is eating disorders. The guideline will look at comorbidities, as outlined in section 1.3-4. However, the inclusion of other medical conditions would have significant resource implications and we are therefore unable to include them in the scope.

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				leukaemia but then developing a very resistant and life-threatening eating in the context of severe emotional grief reaction to her previous health experience. Another one is a girl with both Crohn's disease and anorexia nervosa. The feedback needs to address the issue of this most complex group and why they are apparently excluded from the scope.	
24	Association of Child Psychotherapists	1	0	P1: who the guideline is for Include psychotherapists and child and adolescent psychotherapists in the professional groups listed. Many CAMHS and private sector in-patient and out-patient ED units for both adults and young people employ psychotherapists. (Please note child and adolescent psychotherapy is also a core CAMHS profession.)	Thank you for your comment. We have amended the list to include psychotherapists.
31	Association of School and College Leaders	1	General	It is often the case that the first professionals who become aware of a young person's eating disorder are in schools and colleges. It might be helpful to issue some guidance specifically to educators to improve this identification, particularly at an early stage.	Thank you for your comment. This guideline will be a clinical guideline, and therefore unable to make direct recommendations to education professionals. However, the guideline may make recommendations for how healthcare professionals should work with education professionals to improve access to care as you suggest. However, the purpose of the scope is to set out the areas the guideline will review, rather than make these recommendations.
32	Association of School and	2	General	The present document is focussed on the treatment of eating disorders that have already arisen. Is there any	Thank you for your comment. We agree prevention and awareness are important issues however the

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	College Leaders			opportunity to address the question of how to reduce the incidence of such disorders by taking preventative action?	resource implications of including these areas are significant and as such we are unable to extend the scope.
41	British Association for Behavioural & Cognitive Psychotherapies	1	General	The scope is very comprehensive in what it plans to cover.	Thank you for your comments.
42	British Association for Behavioural & Cognitive Psychotherapies	2	1.3.2	CBT is identified as a therapy for review, which is absolutely appropriate.	Thank you for your comment.
43	British Association for Behavioural & Cognitive Psychotherapies	3	1.3.2	This section refers to '...low intensity interventions, such as self-help and internet-based therapies'. It is suggested that the review should include any brief focused psychological therapies under the umbrella of low-intensity intervention.	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.
4	British Psychological Society	1	1.3.3	Reference to MARSIPAN Guidance should be made	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review, therefore it would not be appropriate to reference other guidance in this section.
5	British Psychological Society	2	1.5.3	Reference to MARSIPAN Guidance should be made	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review, therefore it would not be appropriate to reference other guidance in this section.
6	British Psychological	3	1.5.6	Potential role of day services to be included	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review.

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	Society				This review question will look at all relevant ways of coordinating care for people with eating disorders.
7	British Psychological Society	4	1.5.6	Impact of service structures on service delivery e.g. managed networks of services / introduction of NHS England regional funding of inpatient beds.	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review. This review question will look at all relevant ways of coordinating care for people with eating disorders.
8	British Psychological Society	5	1.5.7	Use of CTO (Care Treatment Orders)	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review. This review question will look at all relevant factors and considerations for when compulsory treatment is used.
50	Care UK	1	General	I would like to see consideration of treatment and types of placements given to Severe and Enduring Eating Disorders (SEEDS) with a view on the appropriateness of residential care as opposed to repeated acute admissions.	Thank you for your helpful comments, they will be taken into account when developing the guideline.
49	College of Mental Health Pharmacy	1	1.3.2	(1.3.2 General comments on pharmacological interventions in eating disorders) Our comments on pharmacological interventions are as follows; - Altered pharmacokinetics in people with eating disorders (due to starvation, vomiting, dehydration or over-hydration) can lead to increased sensitivity or propensity for unwanted adverse effect to medicines. It is therefore, advisable to use lower doses of medicines initially, then assess response and adjust doses accordingly. - Baseline ECG recommended.	Thank you for your comment. The guideline will consider the issues you have helpfully raised when reviewing the evidence and making recommendations based on that evidence. The purpose of the scope is not to make these recommendations, but to set out the areas the guideline will review.

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				- Caution should be exercised with prescribed medicines that prolong QTc interval (such as macrolide antibiotics, antipsychotics, tricyclic antidepressants and Citalopram/escitalopram) and those that exacerbate electrolyte disturbances, especially hypokalaemia. - Recommend that individuals with anorexia nervosa should have an alert placed on their prescribing record to highlight this risk of QTc prolongation (as per current NICE recommendations). - Malnourished patients, with nutritional deficiency and/or chronic debilitating illness are therefore likely to be glutathione deplete e.g. acute or chronic starvation, (patients not eating for a few days), or eating disorders (anorexia OR bulimia). In these individuals with bodyweight less than 50kg, should take a lower dose of paracetamol than the maximum dose recommended to reduce the risk of hepatotoxicity. - Physical health monitoring is essential, such as blood pressure, pulse, temperature and weight, electrocardiography, and blood tests e.g. measure electrolytes, glucose and liver function.	

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				Biochemical abnormalities should be corrected accordingly. - Hypophosphataemia and hypokalaemia is common, and may required oral supplementation to correct low levels. - Thiamine deficiency can be exacerbated when reintroducing food (refeeding), prophylactic supplementation is often recommended when weight gain begins. - Anorexia nervosa is associated with osteoporosis, and can lead to an increased risk of fractures. Bone density and calcium levels should be monitored, prophylactic treatment should be considered. Long-term physical health monitoring is essential. - Caution required in patients with co-existing comorbidities such as depression, anxiety, substance misuse, which could increase the likelihood of drug-drug interactions/ polypharmacy, leading to increase incidence of adverse or unwanted effects. - Caution required when using medicines (prescription only and general sale medicines)	

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				liable for abuse/misuse in people with eating disorders, such as laxatives and diuretics. - Specialist pharmacist advice should be sought on the bioavailability and different formulations of medicines available to administer during nasogastric-feeding, or in patients with swallowing difficulties. - Eating Disorder Specialist Units should have access to specialist pharmacist advice on how to manage pharmacological interventions. - Patients receiving antidepressant treatment should be made aware of discontinuation symptoms upon abrupt withdrawal of antidepressant.	
25	College of Occupational Therapists	1	1.3.2	<u>Activities, services or aspects of care</u> Key areas that will be covered should include: Psycho-social interventions including: - Psycho-educational, experiential, motivational and exploratory life skill training and creative interventions that promote social inclusion, functional enablement and the acquisition of personal recovery goals (eg eating and meal preparation interventions, adaptive lifestyle interventions, social skills interventions and	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.

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				Projective Art interventions) - Creative and recreational interventions that promote engagement in meaningful activity, social contact and enhanced therapeutic alliance.	
61	College of Occupational Therapists	1	1.3.2	Activities, services or aspects of care Key areas that will be covered should include: Psycho-social interventions including: - Psycho-educational, experiential, motivational and exploratory life skill training and creative interventions that promote social inclusion, functional enablement and the acquisition of personal recovery goals (eg eating and meal preparation interventions, adaptive lifestyle interventions, social skills interventions and Projective Art interventions) - Creative and recreational interventions that promote engagement in meaningful activity, social contact and enhanced therapeutic alliance	Thank you for your comment, the evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base - it is not possible to specify what interventions these will be in the scope.
26	College of Occupational Therapists	2	2	NICE guidance about the experience of people using NHS services Should include patient/service user experience specifically related to eating disorders services - NB Guidance on this is essential given that motivational enhancement is such a crucial part of treatment	Thank you for your comment. This section relates specifically to existing NICE guidance and therefore refers to NICE clinical guidelines 136 and 138.
62	College of Occupational	2	2	NICE guidance about the experience of people using NHS services	Thank you for your comment. This section relates specifically to existing NICE guidance and therefore

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	Therapists			Should include patient/service user experience specifically related to eating disorders services - NB Guidance on this is essential given that motivational enhancement is such a crucial part of treatment	refers to NICE clinical guidelines 136 and 138.
44	Department of Health	1	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you.
23	Diabetes UK	1	General	ED-DMT1 is a term used to describe an eating disorder where people with Type 1 diabetes regularly omit insulin in order to lose weight. Diabetics With Eating Disorders (DWED) have published information from a recent survey which estimated that as many as 40% of 15 – 30 year olds with diabetes regularly omit insulin. Omitting insulin can cause rapid weight loss but it also leads to hyperglycaemia and puts the individual at high risk of long-term complications from high blood glucose levels, such as blindness, nerve damage, cardiac disease and stroke. We welcome the fact that this guideline is intended for healthcare professionals who are directly involved in the treatment of eating disorders as well as those who are not. Providing treatment which fully addresses the psychological and physical components of ED-DMTI requires the input of both mental health specialists and diabetes specialists working together. Treating a person with ED-DMT1 for an eating disorder in isolation of their diabetes can be disastrous. This is because, although the	Thank you for your helpful comments, they will be taken into account when developing the guideline.

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				person may present with symptoms representing anorexia or bulimia it is the manipulation of insulin which is the cause of weight loss and not necessarily a limited calorie intake. Therefore, it is crucial that the treatment recognises this, with the input of appropriate diabetes and mental health expertise. To further understand this issue, we would advise NICE to look at areas where diabetes and mental health specialists are working together to offer the type of service that is needed to provide appropriate and comprehensive treatment for people with ED-DMT1. Such a service can be found at Guy's and St Thomas' NHS Foundation Trust and at South London and Maudsley NHS Foundation Trust.	
57	Diabetics With Eating Disorders	1	General	Up to 40% of females who have Type 1 Diabetes admit to missing insulin for weight loss purposes (Fairburn & Peveler 1991) furthermore you are twice as likely to have a clinically diagnosable Eating Disorder if you also have type 1 (Jones, Lawson, Daneman, Olmsted & Rodin 2000). This leads to blindness, amputation, infertility, kidney failure and death. The process of insulin omission, colloquially known as Diabulimia and academically represented under EDDMTI (Eating Disorders in Diabetes Melitus Type 1) must be addressed specifically in these guidelines. Treatment models that do not address diabetes as a mechanism for weight control or understand diabetes specific aspects of an Eating Disorder fail abjectly and in the worst cases these failures result in	Thank you for your comment. We acknowledge the concerns you raise and recognise the importance of these issues however the prime focus of the guideline is eating disorders. The guideline will look at comorbidities, as outlined in section 1.3-4, however the inclusion of other medical conditions would have significant resource implications and are therefore unable to be included in the scope.

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				death. It is well reported that traditional treatment such as CBT is not effective in reducing blood sugar levels in those with Type 1 and an Eating Disorder (Peveler &Fairburn 19992/ Olmsted, Daneman, Rydall, Lawson, & Rodin 2002).) Omission from the guidelines means that we will be treated for illnesses we don't have, wasting everyone's time and money. The Lancet recently published a meta-analysis on all cause mortality and vascular events in women vs men with T1 that showed that women had a 40% excess risk of all cause mortality and twice the risk of fatal and non fatal vascular events compared with men. (Huxley, Peters, Mishra & Woodward 2015). Lets be brutal and honest, this is due to eating disorders, or more appropriately the practice of insulin omission. Every clinician knows it goes on but also knows there is 'nowhere to put' these patients. It is common knowledge that anorexia has the highest mortality rate of any mental illness but while the mortality rate for AN is 7 per 1000 and for type 1 Daiabetes is 2.2, combine the conditions and that mortality rate jumps to a truly depressing 34.6 per 1000 (Nielsen, Emborg &Mølbak 2002). Despite these statistics we have no specialisation and no consensus on what appropriate treatment looks like. But chronic insulin omission IS an Eating Disorder in it's own right, recent research shows that 98% of those who have Diabetes and	

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				an Eating Disorder attribute their illness to Diabulimia, separate in both aetiology and prognosis from Anorexia, Bulimia and BED (Allan 2015 in press). We must have recognition and protection from the NICE clinical guideline otherwise we will continue to die at twice the rate of our male counterparts and 9 times the rate of our non-diabetic counterparts (National Diabetes Audit 2012 – 2013). The boys are however unfortunately catching up and research has shown that males with Type 1 Diabetes have a higher drive for thinness that their non-Diabetic peers (Svensson, Engström & Åman 2003). It is hard enough for women, for men it can be excruciating and near impossible to get help. I would site the case recently reported in the Daily Mail of Rhys Saunders who died of this condition despite repeated calls from his mother, a nurse, for psychological intervention. Her complaint against Hywel Dda Local Health Board has recently been upheld by the ombudsman. If we do survive it tends to be with debilitating complications, which makes us incredibly expensive too. All of that expense can be avoided with proper treatment such as that provided by forward thinking clinicians such as Jane Morris at the EDEN unit and Janet Treasure at the Maudsley who have involved patent input heavily and have some great success stories. Or the amazing team at Guys and St Thomas who aren't afraid to raise the issue with their patients and who I attribute my own recovery to.	

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				Even though they have shown that treating those with Diabetes and an Eating Disorder requires more than business as usual, their innovative approaches stand alone. And they will remain alone if insulin omission for weight loss purposes/ Diabulimia/ or EDDMT1 is not covered comprehensively in this guideline.	
45	Faculty of Sports and Exercise Medicine	1	1.3.1	(1.3.1 and 1.5.1) Identification & Assessment: In the sports and exercise medicine community there is concern about the use of the usual validated screening questionnaires due to their applicability to the athletic and particularly elite sport population. In this population, diet is already tightly controlled and it takes understanding as to when the control on diet has turned to disordered eating. Health service personnel seeing this group need expertise and knowledge of what is normal training and nutrition. Eating disorders are more prevalent than that reported in the general population, particularly in endurance, asthetic and weight restricted sports. Prevalence reported in some larger studies as 31% of female athletes vs. controls 5.5% (Byrne & McLean, J Sci Med Sport 2002); 25% athletes vs 9% controls (Sundgot-Borgen & Torstveit, Clin J Sport Med 2004). In a review from the British Journal of Sports Medicine 2014 Mountjoy et al quote a prevalence of 20% in female adult and 13% adolescent athletes vs. male 8% adult and 3% adolescent athletes.	Thank you for your comment. The guideline will consider the issues you have raised when reviewing the evidence and making recommendations based on that evidence. The purpose of the scope is not to make these recommendations, but to set out the areas the guideline will review.

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				In further assessment what are the recommendations for physical assessment in terms of what blood tests are ordered, other tests such as ECGs and DEXA and their evidence?	
46	Faculty of Sports and Exercise Medicine	2	1.3.3	(1.3.3 and 1.5.3) The management of physical health problems caused by an eating disorder: Physical activity advice needs considered within management. For some an excess amount of activity will be contributing to their disorder. Where this is the case, as they recover, re-introducing exercise may be deemed appropriate and expertise does exist (within the NHS and other providers) in sports and exercise medicine e.g. evidence exists for exercise benefiting self-esteem, impact exercise and strength training can improve bone health. The titration and nature of the exercise undertaken is important to manage so there is no harm.	Thank you for your comment. Although this is too detailed to add to the scope all relevant available evidence will be reviewed for each area of the scope.
47	Faculty of Sports and Exercise Medicine	3	General	Students form a large proportion of the sporting population and they are disadvantaged with services being away from their family and support networks.	Thank you for your comment, we agree that transition between services is important and will be reviewed in key questions on organisation and delivery of services in section 1.5.6.
48	Faculty of Sports and Exercise Medicine	4	General	Elite sports people have their eating disorders picked up at an earlier stage as performance is affected by injury, illness or lack of expected improvement. The UK health system, however struggles to be able to deal with them, often they need to be further down the severity spectrum to get access to help. Therefore costing early intervention and persuading commissioning groups to invest in this is	Thank you for your comment. Although this is too detailed to add to the scope it may be explored in the full guideline.

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				vital.	
69	Kent and Medway Partnership Trust		1.5.2	**Late comment** Please can the scope include evidence on the effectiveness of Occupational Therapy interventions in the treatment of Eating Disorders including qualitative reports.	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.
51	National Osteoporosis Society	1	General	(General - more specifically p.3 area 3 and page 6 issue/question 3) Given that eating disorders are a risk factor for osteoporosis, the National Osteoporosis Society welcomes the inclusion of "..the management of the physical symptoms and negative after effects of eating disorders…such as low bone density…"(page 6 point 3) in the draft scope for this guideline. We look forward to commenting on the draft guideline when it is released for consultation in October.	Thank you for your comments.
64	NHS Choices	1	General	The Digital Assessment Service welcome the guidance and have no comments on its content as part of the consultation.	Thank you.
53	NHS England	1	General	I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you.
27	Nottinghamshire Healthcare NHS Trust	1	General	I am glad that the scope will look across the age range	Thank you for your comments.
65	Nottinghamshire Healthcare NHS	1	General	I am glad that the scope will look across the age range	Thank you for your comments.

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	Trust				
28	Nottinghamshire Healthcare NHS Trust	2	1.1	I am very concerned by the exclusion of ARFID from the scope, and it is not consistent with the current service provision in much of the UK. My argument for inclusion of ARFID includes: 1) The DSM-5 criteria have a single category of "Feeding and Eating Disorders", and I am unsure that it is valid to exclude it as such on the basis of "not being an eating disorder"; 2) Highly Specialist ED provision within the UK (e.g. the Intensive Treatment Programme provided by South London and Maudsley, commissioned directly by NHS England as an alternative to inpatient treatment for ED) include ARFID as part of their criteria; similarly, within our community CAMHS ED service, young people who best meet the criteria for ARFID are often judged to be most appropriately treated by our service with our ED-based skills; 3) Differentially diagnosing ARFID from Anorexia is by no means straightforward. In particular, the primary distinguishing factor is a lack of desire to lose weight, or no body image distortions – however, these factors rely primarily on self-report, which is itself an unreliable data source. Furthermore, it is very difficult to establish the absence of fear of food in ARFID unless behavioural change has been attempted by the family; this is often not the case. The diagnostic uncertainty suggests that ARFID in adolescents may well require a similar approach to Anorexia, and this should be explored within the guidance, even if the findings emerge to be inconclusive.	Thank you for your comments. We recognise the clinical utility of ARFID and the ongoing ambiguity regarding its differentiation from other feeding disorders. However, it is a relatively new diagnostic category and one for which there is as yet little in the way of evidence on which to make recommendations. As such, inclusion in the scope would utilise disproportionate resources for relatively low yield/added value.

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66	Nottinghamshire Healthcare NHS Trust	2	1.1	I am very concerned by the exclusion of ARFID from the scope, and it is not consistent with the current service provision in much of the UK. My argument for inclusion of ARFID includes: 1) The DSM-5 criteria have a single category of "Feeding and Eating Disorders", and I am unsure that it is valid to exclude it as such on the basis of "not being an eating disorder"; 2) Highly Specialist ED provision within the UK (e.g. the Intensive Treatment Programme provided by South London and Maudsley, commissioned directly by NHS England as an alternative to inpatient treatment for ED) include ARFID as part of their criteria; similarly, within our community CAMHS ED service, young people who best meet the criteria for ARFID are often judged to be most appropriately treated by our service with our ED-based skills; 3) Differentially diagnosing ARFID from Anorexia is by no means straightforward. In particular, the primary distinguishing factor is a lack of desire to lose weight, or no body image distortions – however, these factors rely primarily on self-report, which is itself an unreliable data source. Furthermore, it is very difficult to establish the absence of fear of food in ARFID unless behavioural change has been attempted by the family; this is often not the case. The diagnostic uncertainty suggests that ARFID in adolescents may well require a similar approach to Anorexia, and this should be explored within the guidance, even if the findings emerge to be inconclusive.	Thank you for your comments. We recognise the clinical utility of ARFID and the ongoing ambiguity regarding its differentiation from other eating disorders. However, it is a relatively new diagnostic category and one for which there is as yet little in the way of evidence on which to make recommendations. As such, inclusion in the scope will utilise disproportionate resources for relatively low yield/added value.
29	Nottinghamshire	3	1.5.2	Although the scope states that children and YP are	Thank you for your comment. We will be looking at the

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	Healthcare NHS Trust			included in the scope, this section should make explicit reference to the fact that evidence exploring the differences between interventions for adults and young people will be examined – "Does any psychological or pharmacological intervention have evidence for effectiveness in people under the age of 18"	evidence for children, young people and adults.
67	Nottinghamshire Healthcare NHS Trust	3	1.5.2	Although the scope states that children and YP are included in the scope, this section should make explicit reference to the fact that evidence exploring the differences between interventions for adults and young people will be examined – "Does any psychological or pharmacological intervention have evidence for effectiveness in people under the age of 18"	Thank you for your comment. We will be looking at the evidence for children, young people and adults.
30	Nottinghamshire Healthcare NHS Trust	4	1.5.3	Although the scope states that children and YP are included in the scope, this section should make explicit reference to the fact that evidence exploring the differences between physical management for adults and young people will be examined – "What are the key differences in managing physical health for people under the age of 18?"	Thank you for your comment. We will be looking at the evidence for children, young people and adults.
68	Nottinghamshire Healthcare NHS Trust	4	1.5.3	Although the scope states that children and YP are included in the scope, this section should make explicit reference to the fact that evidence exploring the differences between physical management for adults and young people will be examined – "What are the key differences in managing physical health for people under the age of 18?"	Thank you for your comment. We will be looking at the evidence for children, young people and adults.
63	Rotherham	1	General	Agree with scope and exclusions	Thank you for your comments.

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	Doncaster & South Humber NHS Trust				
33	Royal College of General Practitioners	1	General	This thoughtful scope should enable a difficult area of medicine to be approached and a better understanding of the problem. It would be helpful to have consideration of the Natural History of eating disorders – they often seem to have a peak in the population and at their most intense in the patient (15-25) and resolve with age. The epidemiology is critical – Time, Place, Person, Incidence, Prevalence, Morbidity, Mortality, Present interventions/treatment, Cost of Care, Evidence of effectiveness. (PS) I would emphasise that from a Primary Care perspective, Eating Disorders are often under-reported and under-recognised and may manifest in other symptoms e.g. abdominal pains, headaches. Often direct questioning about eating is need to elucidate a good history. There is inadequate NHS provision for eating disorders especially those needing inpatient input. In high risk environments for eating disorders (e.g. private secondary girls' schools), school nurses should screen for evidence of eating disorders. The overlap with depression and anxiety needs elucidating. (DM) I have concerns that the consultation scope will not	Thank you for your comments. The evidence that eating disorders resolve in time is shaky. We are aware of evidence that epidemiological factors (age, gender, etc.) influence treatment outcomes, beyond the issue that younger cases and older cases do better with FBT and CBT respectively. We are aware that you may be referring to developmental differences in presentation rather than natural history. Developmental differences in assessment and management will be covered.

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				identify the current failures in the provision of services. Eating disorders affects the whole family and requires considerable family support. Family therapy to help communication can make substantial impact. Currently young people and their families suffer because of a lack of care up to 25 years but meet and fail at the transition barriers between CAHMS and adult mental services. Students that live away from home also suffer with lack of continuity between their home health services where they are resident up to 5 months per year and their higher education institution where are present for 7 months a year. Medical Students who move across different areas have considerable difficulties getting continuity of care. Professionals can struggle with confidentiality and models of care such as the triangle of care to involve the families taking an active role is important for the survival of ongoing relationships. (MH)	We will address the organisation and delivery of services (section 1.5.2) which includes transitions between services. This will cover the important role families and carers have and how to help carers of with an eating disorder (see section 1.5.5).
54	Royal College of Midwives	1	General	The RCM is pleased to see that this guideline is being updated.	Thank you for your comments.
55	Royal College of Midwives	2	0	(Introduction) Midwives should be included in the list of professional groups who are involved in the recognition of eating disorders. Midwives have an significant public health role and are frequently the first point of contact that a woman may have with the health services. It is unlikely that midwives will identify recommendations that are relevant to their practice unless that is clearly	Thank you for your comment. The list of professions included in the scope is not intended as an exhaustive list of all professions but rather to provide examples of the broad representation of health and non-health sectors the guideline is intended for.

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				documented. In this context we think it is important to have a midwife as a member of the GDG.	
56	Royal College of Midwives	3	2	There should be a clear link to the guidance on antenatal and postnatal mental health (NICE guideline CG 9) as well as the guidance on maternal and child nutrition (NICE guideline PH11). The guideline on antenatal and postnatal mental health does recommend "Offering a psychological intervention in line with the guideline on eating disorders" yet there is no mention of pregnant women in the scope for the update here.	Thank you for your comment. We agree this is an important issue and where appropriate will cross reference to the relevant guidelines in the development of the guideline.
1	Royal College of Nursing	1	1	We feel that that the guidance focusses mainly on anorexia and bulimia. Will other eating disorders be mentioned? We think that it is worthwhile identifying that these are not the only eating disorders and listing others, even if they are not addressed in detail.	Thank you for your comment. We have amended section 1 to make it clear that other eating disorders will also be included in the guideline.
2	Royal College of Nursing	2	1.3	The physical manifestations of the disorder; this section could, potentially, be huge. How much detail will be provided here and if possible will therapeutic responses/ interventions be listed here (or cross referenced)?	Thank you for your comment. All relevant available evidence will be reviewed for each area of the scope, although we are unable to detail at this stage how much this will be for each intervention.
3	Royal College of Nursing	3	1.5	Sometimes, when compulsory treatment is required and tube feeding is implemented, the patient resists the administration of the feed. This may mean that the feed needs to be given under restraint. There is much concern about the frailty of the patient and the use of appropriate restraint techniques in this situation. We think that that it is worth a including, or at least a cross-reference to other	Thank you for your comment. The issue of restraint will be addressed (including any form of constraining interventions) as outlined in section 1.5.7. Other guidelines may well be cross-referenced, although we cannot anticipate what the guideline will say.

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				guidance in this area.	
58	Royal College of Paediatrics and Child Health	1	General	(General / Whole document) General paediatricians sometimes get asked to provide medical input to Eating disorder patients (usually at 4pm on a Friday when FEDS worry about bradycardia or re-feeding syndrome). There is no real training or expertise with these patients. They not infrequently end up being admitted onto a general acute ward overnight or the weekend because there is nowhere else for them to go. They may have someone from CAMHS visit, they may not. There are no nurses employed with a special interest or experience in these young people and no RMNs are brought in. We feel that the standards should set out the minimum competences that must be in place before these needy & vulnerable people are admitted to a facility & CAMHS and the CCGs should proactively collaborate to commission & establish such a facility available in each locality. CCGs may even need to collaborate. This facility almost certainly doesn't need to be at every local DGH, but probably at a regional hospital. We would suggest there may need to be an HDU for managing critical refeeding, the constant availability of a	Thank you for your comments. Whilst training is relevant, in particular the impact of training on outcomes, it is outside of this scope to set minimum competencies for practices, even though it is important. However, where we find evidence for the effectiveness of psychological or other interventions, we will aim to spell out the skills/competencies of the professionals providing care in the underlying trials and recommend these for practice in the NHS.

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				paediatric dietitian with an interest in EDs, a paediatrician with an interest (not one coerced) in EDs, CAMHS clinicians available 24/7 for advice including to review the patient in person (not over the phone like here) and skilled ED experienced & trained nurses.	
16	South West Yorkshire Partnership NHSFT	1	1.3	Section 1 – examples of tools are Eating Disorder Inventory (EDI) or Eating Attitudes Test (EAT-26) which are both self-reported by the patient.	Thank you for your comment, the review of assessment tools will review all relevant tools in this area.
17	South West Yorkshire Partnership NHSFT	2	1.3	Section 2 – change wording from "Interventions to treat eating disorders through all phases of the disorder" to "Interventions to treat eating disorders through all stages of change"	Thank you for your comment. While the intent of interventions is change we cannot assume it will always be an outcome so have kept the wording as it is in the scope.
18	South West Yorkshire Partnership NHSFT	3	1.3	Section 2 – psychological interventions to include use of family based therapy for university patients.	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.
19	South West Yorkshire Partnership NHSFT	4	1.3	Section 2 – psychological interventions to include using concepts from family based therapy for married couples. (These models employ the use of social support concepts).	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.
20	South West Yorkshire	5	1.3	Section 2 – change "nutritional interventions, including tube feeding" to "nutritional interventions, including	Thank you for your comment, the purpose of the scope is to set out the areas the guideline will look at rather

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	Partnership NHSFT			nutritional counselling and tube feeding, by a registered specialist eating disorder dietician."	than to make recommendations about how should deliver specific interventions – the guideline will consider this.
21	South West Yorkshire Partnership NHSFT	6	1.3	Section 2 – add – other modalities – day treatment programmes for adolescents who do not improve in family based therapy.	Thank you for your comment, the examples given are not intended as an exhaustive list. The evidence for the interventions in this area will be searched for and recommendations made on those that have a clear evidence base, which may include the intervention you have suggested.
22	South West Yorkshire Partnership NHSFT	7	1.3	Proposed new section – section 8 – MDT as standard in care of eating disorders – to include nutrition, medical and mental health professionals. Provides comprehensive treatment with each team member contributing best when grounded in advances training in eating disorders. Teams need to be co-ordinated for consistent communication and to avoid "splitting".	Thank you for your comment. The most effective service configurations will be reviewed by the guideline, which is covered by *1.3-6: Organisation and delivery of services to support practitioners in the effective and competent delivery of interventions*.
59	Student Minds	1	General	<u>Consider university students as a special interest group and take account of their specific needs as a transient community.</u> The transition to university involves moving away from established support networks and students receiving specialist support for eating disorders may be leaving behind established therapeutic relationships with clinicians. In the process of this transition, students are commonly discharged from the specialist service that has been supporting them at home. Registering with a new GP, in a new city, commonly leaves gaps in the treatment and support these students receive. This transition is a	Thank you for your comment, we agree that transition between services is important and is included in key questions on organisation and delivery of services in section 1.5.6.

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				crucial time for the delivery of support to students with eating disorders and yet there are few mental health services providing targeted support for their needs.	
60	Student Minds	2	1.3.6	'Organisation and delivery of services' to include the organisation of services across points of transition, particularly in relation to the transient student population. Students live transient lifestyles, living at home during the holidays and at university during term-time. Most students spend over 25 weeks of the year living away from the city in which they are permanently registered with a GP. This is a substantial barrier to providing consistent care for students. Key information is being lost between home and university GPs and the process of re-telling a medical history to many doctors through these transitions is exhausting and stressful for students. Students are also facing practical challenges in accessing vital medical support as they move between their registered GP service at university and visiting their home GP service as a temporary patient during the university vacations. When accessing care as a temporary patient, students report having limited access to services ranging from blood tests to psychological support. Students also have specific needs in relation to the academic calendar. Due to the high demand for psychological therapies, it can take months to progress up a waiting list to receive care. It is not uncommon for students to reach the top of the waiting list for specialist	Thank you for your comment, we agree that transition between services is important and will be reviewed in key questions on organisation and delivery of services in section 1.5.6.

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				care in their university locality when they are back at home during the holidays or when they are about to sit university exams. If patients cannot attend the sessions assigned to them, they are usually dropped off the waiting list and required to go through the referral process again. Further information on the impact of university transitions on access to treatment for students with eating disorders can be found in the Student Minds 'University Challenge' report, 2014. [http://www.studentminds.org.uk/uploads/3/7/8/4/3784584/university_challenge.pdf]	
34	Tees Esk and Wear Valley NHS Trust	1	1.3.3	Reference to MARSIPAN Guidance should be made	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review, therefore it would not be appropriate to reference other guidance in this section.
35	Tees Esk and Wear Valley NHS Trust	2	1.5.3	Reference to MARSIPAN Guidance should be made	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review, therefore it would not be appropriate to reference other guidance in this section.
36	Tees Esk and Wear Valley NHS Trust	3	1.5.6	Potential role of day services to be included	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review. This review question will look at all relevant ways of coordinating care for people with eating disorders.
37	Tees Esk and Wear Valley NHS Trust	4	1.5.6	Impact of service structures on service delivery e.g. managed networks of services / introduction of NHS England regional funding of inpatient beds.	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review. This review question will look at all relevant ways of coordinating care for people with eating disorders.

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38	Tees Esk and Wear Valley NHS Trust	5	1.5.7	Use of CTO (Care Treatment Orders)	Thank you for your comment. The purpose of the scope is to set out the areas the guideline will review. This review question will look at all relevant factors and considerations for when compulsory treatment is used.
39	Tees Esk and Wear Valley NHS Trust	6	General	I know the intention of the document is to develop guidance that is ageless in its scope, but wonder what impact this may have in the development of community treatment, particularly with patients that would perhaps have been open to MHSOP prior to this document. From our services point of view, we have done much work around the transition of care from CAMHS to AMHS and also the transition of care between specialist ED services and more generic mental health services. It would be nice to think that our service will have the opportunity to share what has been achieved.	Thank you for your comments. We are aware that your trust has done some very good work in this area. However, it would be problematic to use the experience of an individual trust as evidence within a NICE guideline.
40	Tees Esk and Wear Valley NHS Trust	7	General	Perhaps another area that may be useful for clarity from our services perspective, is that of who care co-ordination responsibilities should rest with, particularly when a patient has a complex presentation and multiple diagnosis (although this may be outside of the scope of the guideline).	Thank you for your comment. Unless there are very good reasons to do so, we do not typically identify specific professional groups to undertake specific interventions or practices.

Registered stakeholders: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0703/documents