CHILDHOOD CONSTIPATION – scope consultation comments table (30 Jan – 26 February 2008)

Status	Organisation	Order no.	Section	Comments	Responses
SH	Action for Sick Children			This organisation was approached but did not respond.	
SH	Addenbrookes Hospital, Cambridge University Hospital NHS Trust			This organisation was approached but did not respond.	
SH	Airedale and Bradford Teaching PCT			This organisation was approached but did not respond.	
SH	Airedale NHS Trust	1	3 d	States constipation may cause faecal retention. I would think constipation always involves faecal retention and best to leave out .	Thank you. This will be amended in the updated scope.
SH	Airedale NHS Trust	2	3 d	No mention of faecal soiling in this section!	Thank you. This is mentioned in another area of the scope
SH	Airedale NHS Trust	3	3 a	In my experience the concept of hard stools is not shared by parents and advisers especially if the child leaks soft stool. The passage of large stools might be better. Or the passage of large (not necessarily hard) or hard stools. Hard stools may be fine e.g. in sheep it's the ones that stick together to form big lumps that in my experience are the problem	Thank you. The definition of constipation will be discussed by the GDG and presented in the guideline.
SH	Airedale NHS Trust	4	3 g	Re Hirschsprung's disease. In this neurological condition since the bowel cannot relax large stools are not a feature.	Thank you. Hirschprung's is excluded from the scope.
SH	Airedale NHS Trust	5	4.3 b bullet point 4	Too many questions in one section. I am not sure I know the difference between soiling and incontinence.	Thank you. Definitions will be covered.
SH	Airedale NHS Trust	6	4.3 b	A good discriminator for Hirschsprung's disease is age at first passage of meconium. If passed in first 48 hours condition is unlikely. This should be specifically asked instead of bullet point 5	Yes, we agree. Detailed history-taking will be underlined in the guideline.
SH	Airedale NHS Trust	7	4.3 b	Suggest a question on school refusal. P.E and swimming days	Thank you. This will be covered in the history taking.
SH	Airedale NHS Trust	8	4.3 b	Where does he hide his underwear. This often causes a lot of aggression and is normal if soiling	Thank you. This will be covered in the history taking.
SH	Airedale NHS Trust	9	4.3 b	Affect of constipation on eating behaviour. If no bowel action then child avoids eating and activating the gastro colic reflex. This question aids diagnosis and discussion	Thank you. This will be covered in the history taking.

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SH	Airedale NHS Trust	10	General	Perhaps break this section into 2 General questions and specific to those with soiling	Thank you. The scope has now been amended and soiling is not mentioned independently from constipation.
SH	Association for Continence Advice			This organisation was approached but did not respond.	
SH	Association of Psychoanalytic Psychotherapy in the NHS			This organisation was approached but did not respond.	
SH	Association of the British Pharmaceuticals Industry,(ABPI)			This organisation was approached but did not respond.	
SH	Autism Medical			This organisation was approached but did not respond.	
SH	Barnsley Hospital NHS Foundation Trust			This organisation was approached but did not respond.	
SH	Bedfordshire PCT	1	4.3 h	Need to include early years provision, for education and recognition of problems. This may cover childminders, nurseries, child day care centres. Also need to include looked after children services .	Thank you. The guideline is intended to cover all health care settings.
SH	Boehringer Ingelheim Ltd			This organisation was approached but did not respond.	
SH	Bolton Council			This organisation was approached but did not respond.	
SH	Bournemouth and Poole PCT			This organisation was approached but did not respond.	
SH	British Association for Community Child Health	1	General	Main concern is the appropriate use of laxatives. As paediatricians and paediatric gastroenterologists agree, children often need doses of laxatives that are well above the doses suggested in the BNF. Most of this prescribing is based on experience, indeed many years experience. Evidence in terms of RCTs is hard to find. It is crucial that this experience is considered when recommending doses	Thank you. This is a very important issue and will be carefully considered.
SH	British Association for Community Child Health	2	General	Some newer drugs have RCTs to back them up. This does not however necessarily mean that these newer drugs are superior to medications that have been used safely for many years. Movicol, for example, is a very useful new	Thank you. The clinical and cost effectiveness will be considered as part of the guideline.

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				medication that is often used, but should not replace the use of other cheaper alternatives, such as lactulose, which for many children is adequate.	
SH	British Association for Community Child Health	3	3 c	Families do indeed often delay seeking help. Part of the scope should therefore include awareness raising among the general public that help can be found, initially via primary care.	Thank you. The 'Understanding NICE guidance' which is a publication for the general public will be developed to help raise awareness amongst the general public.
SH	British Association for Community Child Health	4	4.1.2	As was raised at the recent meeting in London, this list of "groups that will not be covered" needs to be explicit in explaining that children who have the conditions mentioned, such as "known neurological conditions" will be INCLUDED in as much as their FUNCTIONAL constipation can be treated in a similar way as any other child (understanding that treatment of a neurological cause of constipation is not included)	Thank you. This group will be included in the scope.
SH	British Association for Community Child Health	5	4.3 b History	Should include questions about blood in the stools, pain on defaecation and resistance to laxatives (the latter being an indicator to consider another cause of constipation, such as cow's milk intolerance.) Also ask about availability of water at school.	Thank you. This will be covered under history taking.
SH	British Association for Community Child Health	6	4.3 c	Rectal examination is NOT routinely required (may be indicated in some cases, eg neonate with ? Hirschsprung's)	Thank you. Role of DRE will be the subject of a systematic review and considered by the GDG.
SH	British Association for Community Child Health	7	4.3 e	Blood tests not usually needed unless history suggests other problem	Thank you. This will be considered during GDG discussion.
SH	British Association for Community Child Health	8	4.3 f	Radiology rarely required	Thank you. The risk and benefits will be considered fully.
SH	British Association for Community Child Health	9	4.3 g	Manometry a specialist tool	Thank you. The risk and benefits will be considered.
SH	British Association for Community Child Health	10	4.3 h point 4	Intense psychotherapy. Wonder what this refers to. Presumably children who have been abused and often present with "soiling", or more often, encopresis. A cross reference to encopresis and how to differentiate from soiling is very important, as well as a reference to child abuse in all its forms, especially sexual abuse, which can result in both encopresis and soiling or both.	Thank you we agree. We will amend this section to include psychological and behavioural management rather than intense psychotherapy.

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SH	British Association for Community Child Health	11	4.3 h point 5	Enemas and suppositories are rarely needed. Especially in the group mentioned above, they can make the problem worse.	Thank you. The risks and benefits of different therapies will be discussed by the GDG.
SH	British Association for Community Child Health	12	4.3 h	Point about guideline recommendations that "normally fall within licensed indications" is a concern that has been addressed in comment nos.1 and 2	Thank you. We recognise this and the GDG will take this issue seriously.
SH	British Association for Community Child Health	13	General	A guideline about constipation in children needs to include how to manage soiling which is a symptom of significant constipation/ megarectum. This cannot be ignored.	Thank you we agree.
SH	British Association for Community Child Health	14	General	Will the guideline consider pathways of care that have been developed in some areas to manage continence problems in children (including constipation and soiling), which includes the training of school nurses in delivering a service backed up by primary care and local paediatricians? (Such a pathway has been developed in Northumberland).	Thank you. Service delivery falls outside the remit of the scope.
SH	British Heart Foundation Health Promotion Research Group			This organisation was approached but did not respond.	
SH	British National Formulary (BNF)			This organisation was approached but did not respond.	
SH	British Paediatric Mental Health Group			This organisation was approached but did not respond.	
SH	British Society of Paediatric Gastroenterology, Hepatology & Nutrition	1	General	There does not seem to be any mention of transition, essential for the more severe patients. This needs including.	Thank you. Criteria for referral will be considered.
SH	British Society of Paediatric Gastroenterology, Hepatology & Nutrition	2	4.1.2	Many of these patients will have functional constipation (often severe) and require similar management and care and so completely excluding them as a group is inappropriate.	Thank you. These groups of children will be included in the scope regarding the principles of assessment and management of their idiopathic constipation. Any additional care these children may need is not covered within the scope of this guideline.
SH	British Society of Paediatric Gastroenterology, Hepatology & Nutrition	3	4.2	Tertiary care should be part of this, later in the guidelines manometry is included, this is available only in tertiary units.	Thank you. All healthcare settings will be covered.
SH	British Society of Paediatric Gastroenterology, Hepatology	4	4.3 h	Surgical management should include ACE procedures (which will also be part of tertiary care)	Thank you. Risks and benefits of surgical interventions will be considered.

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	& Nutrition				
SH	Calderdale PCT			This organisation was approached but did not respond.	
SH	Central Surrey Health NHS Trust			This organisation was approached but did not respond.	
SH	Chartered Physiotherapists Promoting Continence (CPPC)			This organisation was approached but did not respond.	
SH	CIS'ters			This organisation was approached but did not respond.	
SH	Commission for Social Care Inspection			This organisation was approached but did not respond.	
SH	Connecting for Health			This organisation was approached but did not respond.	
SH	Cornwall & Isles of Scilly PCT			This organisation was approached but did not respond.	
SH	Department of Health	1	4.1.2 c	'children with any known neurological condition, including disorders affecting the spine and brain that can affect bowel movement'. We feel that this excludes disabled children in whom lack of mobility may result in constipation, rather than a direct neurological effect on bowel movement. The issues of medicines for disabled children are highlighted in the NSF and in our view, it is inappropriate that they should be excluded.	This group will be included in the scope where appropriate regarding the principles of assessment and management of their idiopathic constipation. Where there are clear differences this will not be possible. Any additional care these children may need is not covered within the scope of this guideline.
SH	Department of Health	2	General	We suspect that there is as much variation in practice in managing constipation in this group as for other children and in our opinion, it is certainly a common problem in both primary and secondary care.	Thank you we agree.

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SH	Department of Health, Social Security and Public Safety of Northern Ireland			This organisation was approached but did not respond.	
SH	Devon PCT			This organisation was approached but did not respond. This organisation was approached but did not respond.	
SH	East Sussex Hospitals Acute Trust			This organisation was approached but did not respond.	
SH	Education and Resources for Improving Childhood Continence			This organisation was approached but did not respond.	
SH	Griffiths and Nielsen			This organisation was approached but did not respond.	
SH	Healthcare Commission			This organisation was approached but did not respond.	
SH	Heart of England NHS Foundation Trust			This organisation was approached but did not respond.	
SH	Institute of biomedical Science			This organisation was approached but did not respond.	
SH	Kirklees Primary Care Trust			This organisation was approached but did not respond.	
SH	Leeds PCT	1	4.3 h) Clinical management	Dietary modification including the role of water and milk intake, fresh fruit juices (Apple/pear/prune), fruits and vegetables, wholegrain cereals, (fibre and roughage). (In a very small percentage of children Cow's milk intolerance may exacerbate constipation, if milk needs a trial exclusion this should be managed by a Dietitian.)	Thank you. The role of diet will be discussed.
SH	Leeds PCT	1	general	There is very little mention of faecal soiling and there possibly should be both in the initial management and subsequent referral pathway	Thank you. The main focus of the guideline is the assessment and management of constipation. Where appropriate faecal soiling will also be addressed.
SH	Leeds PCT	2	general	There needs to be consideration at assessment of any emotional/traumatic events which can be a trigger factor for childhood constipation ie bereavement	Thank you. This will be covered when history is considered.
SH	Leeds PCT	2	General	If there is any evidence about the role of physical activity in the management of constipation, this should be included.	Thank you. This will be covered when history is considered.

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SH	Liverpool PCT			This organisation was approached but did not respond.	
SH	Luton & Dunstable Hospital NHS Foundation Trust			This organisation was approached but did not respond.	
SH	Medicines and Healthcare Products Regulatory Agency (MHRA)			This organisation was approached but did not respond.	
SH	Medicines for Children Research Network (MCRN)			This organisation was approached but did not respond.	
SH	Milton Keynes PCT			This organisation was approached but did not respond.	
SH	National Patient Safety Agency (NPSA)			This organisation was approached but did not respond.	
SH	National Pharmacy Association			This organisation was approached but did not respond.	
SH	National Public Health Service - Wales	1		NPHS Wales has no comments to make on this draft guidance	Thank you.
SH	Neonatal & Paediatric Pharmacists Group (NPPG)			This organisation was approached but did not respond.	
SH	Newham University Hospital NHS Trust			This organisation was approached but did not respond.	
SH	NHS Clinical Knowledge Summaries service	1	3 e)	1) there are two separate Rome III definitions for functional constipation: 1 for children <4 years old and 1 for children ≥ 4 years old, but only that for older children was quoted. Hyman PE, et al. Childhood functional gastrointestinal disorders: neonate/toddler. Gastroenterology. 2006 Apr;130(5):1519-26. Rasquin A, et al Childhood functional gastrointestinal disorders: child/adolescent. Gastroenterology. 2006 Apr;130(5):1527-37 2) there are two important errors in the way the Rome III definition was quoted. The Rome III definition actually says “child with a ***developmental*** age of at least 4 years with ***insufficient criteria for diagnosis of IBS***”.	Thank you. The definitions will be discussed by the GDG and research criteria will be balanced against practical child centred definitions. We will ensure the definitions in the guideline cover all children’s age groups.

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				The scope should either make accurate quotations, or explain why the definitions have been changed.	
SH	NHS Clinical Knowledge Summaries service	2	3 h)	One study validated the Rome II criteria for use in a Canadian paediatric gastroenterology service. As far as I am aware, there is no evidence to suggest that the Rome III criteria are useful in primary care.	Thank you. Definitions and their relevance to the management of constipation will be discussed and considered by the GDG.
SH	NHS Clinical Knowledge Summaries service	3	4.1.2 c)	Do you want to say "with ***developmental*** or neurological …" ?	Thank you. This section has been reworded to afford greater clarity.
SH	NHS Clinical Knowledge Summaries service	4	4.1.2	Do you want to say that many of the children with conditions in the following list will have constipation and the principles of assessment and management recommended in the guideline will apply to them. However, the guideline's scope does not extend to the additional management that these children might require ?	Thank you for this helpful suggestion which we will now integrate into the amended scope.
SH	NHS Clinical Knowledge Summaries service	5	4.3	This section has unnecessary detail and would be clearer about what the scope if the headings were articulated as (high level) questions. For example: When should constipation be suspected? How should constipation be diagnosed? What items in the history are useful/not useful? What items in the physical examination are useful/not useful? In particular, (i) when, if ever, would the value of information obtained from digital examination exceed the cost (hassle for the clinician; discomfort, pain, indignity for the patient); (ii) could peri-anal palpation be used instead of DRE? What special investigations are useful/not useful for ruling out other conditions in the differential diagnosis? How should constipation be assessed?	Thank you. The scope will be amended.

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				Assessment should guide initial management, followup, and audit It might be useful to distinguish (i) short-duration constipation from chronic; and (ii) mild/moderate/severe/fecal loading ; and (iii) no soiling/soiling. This section would include a discussion of special investigations such as abdominal xray that are used to assess severity and response. Assessment should include the impact on the child and family and school Assessment should include evaluation of risk factors, in particular physical, sexual, and emotional abuse. How should constipation be treated Diet and lifestyle Behavioural and psychological approaches Pharmacological For relief For disimpaction (induction) For maintenance How to stop treatment When should a primary health care practitioner refer a child with constipation to a specialist: Paediatrician Gastro-enterologist Mental health Other	
SH	NHS Clinical Knowledge Summaries service	6	4.3 h)	Laxative product licences are often not helpful, and sometimes discriminatory, for young children and infants. It is therefore important to be transparent about what evidence would be required to support recommendations to prescibe laxatives off-label. Conventionally, placebo-controlled RCTs are required to demonstrate effectiveness. However, this is not appropriate for laxatives. RCTs are	Thank you. This is an important issue that will be considered during the guideline development.

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				essential for unbiased evaluation of ***moderate*** effects. Laxatives have such dramatic effects that simple observation provides adequate evidence of effectiveness. (Any doubter should volunteer for an enema.) Care also needs to taken to specify what evidence is regarded as eligible for consideration of the relative effectiveness of different laxatives. Many of the RCTs compare one laxative at a fixed dose with another laxative, also at a fixed dose. This is not how laxatives are used in practice (the dose is titrated to the effects); and is open to manipulation by the study designers to bias the results in a preferred direction. These studies should be excluded from consideration. Useful evidence would be provided by RCTs of ***strategies*** to treat constipation, with the outcome being comfortable defecation off treatment. I suspect that there will not be many trials to find, so expert opinion will be important (and perhaps the best) evidence. It may require some planning and resource allocation to ensure that the best expert opinion is obtained. Evidence from trials of laxatives in adults are relevant to children, and should be included in the review. Trials of behavioural and psychological approaches in adults are much less likely to be relevant to children, and should be excluded from the review.	
SH	NHS Direct			This organisation was approached but did not respond.	
SH	NHS Plus			This organisation was approached but did not respond.	
SH	NHS Quality Improvement Scotland			This organisation was approached but did not respond.	
SH	Norgine Pharmaceuticals Ltd	1	2 a	It is stated that the guideline will provide recommendations for good practice that are based	Thank you for your comments. The nature of systematic reviewing means that we cannot define

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				on the best available evidence of clinical and cost effectiveness. We consider that the process followed in areas where there is little or no evidence should be defined in the scope.	areas of no evidence until the review is completed.
SH	Norgine Pharmaceuticals Ltd	2	3	This section of the scope contains a number of statements which we do not consider to be accurate, e.g. the definition of fissures. We have not commented on these in detail, but consider that the content of this section requires discussion and consensus by the GDG prior to inclusion as it stands in the Guideline.	Thank you. Definition will be defined by the GDG and included in the glossary of the full guideline.
SH	Norgine Pharmaceuticals Ltd	3	4.1.1	We believe that "faecal impaction/loading" also needs to be defined in this section since although it may be considered as a part of the spectrum of constipation, it is frequently also referred to as a separate entity.	Thank you. Definitions will be addressed by GDG.
SH	Norgine Pharmaceuticals Ltd	4	4.3 h)	This section covers management from a perspective of the mode of treatment. However, the practical management of childhood constipation requires the following phases of management: management of the presenting episode (frequently acute); maintenance of normal bowel habit; and prevention of recurrence. We propose that the management section includes such an approach.	Thank you. We will consider this when the GDG considers the management section.
SH	Norgine Pharmaceuticals Ltd	5	4.3 h) Final paragraph	With regard to the use of unlicensed products, we consider that it should be stated that unlicensed products should only be used where there is clear evidence of efficacy and safety and no licensed product(s) are available for that indication.	Thank you. This is an important point that needs careful consideration by the GDG and available evidence will need to be reviewed.
SH	North East Wales NHS Trust	1	1	Title Functional is probably a better term than idiopathic	Thank you we consider that idiopathic better reflects the content of the guideline.
SH	North East Wales NHS Trust	2	3	Important to emphasise that children do not 'grow out' chronic constipation and that constipated children and adolescents do not spontaneously resolve as they become adults.	Thank you. This will be added in the clinical need section of the scope.
SH	North East Wales NHS Trust	3	3	Need to emphasise the impact of this condition on the child, their family and carers. There are several quality of life studies that have been done that show this condition's negative impact.	Thank you. The guideline will be child centred and the impact on families will be addressed.

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				I would not necessarily agree that families delay seeking help because they feel that the condition is not taken seriously by health care professionals; the problem is that families often seek help and are often fobbed off by health care professionals . There have been studies undertaken to show this	
SH	North East Wales NHS Trust	4	3 d	I think that part of the 'vicious cycle' of constipation has been missed out. Faecal retention is not necessarily caused by fissures but may occur with pain on defecation without fissures.	Thank you. Details regarding problems associated with constipation have now been removed from the scope. Key areas of clinical management have been identified and described.
SH	North East Wales NHS Trust	5	3 e	Need to decide what definition of constipation is used either PACCT or ROME III, but do we need to include Digital Rectal Examination (DRE) in diagnostic criteria because: 1) There is little evidence that DRE is of any diagnostic value 2) There is a lot evidence to suggest that the procedure is not well tolerated by children 3) Most practitioner in this field, rarely if ever undertake a DRE 4) It must not be forgotten that many of the health care professionals who care for these children are nursing staff who are either not trained or unwilling to undertake a DRE.	Thank you. The definition will be discussed and evidence for the use of DRE will be reviewed.
SH	North East Wales NHS Trust	6	3 g	If feel that there is little evidence and it is pejorative to suggest that child become constipated because they are too busy playing to go to the toilet. There is little evidence for this and I feel that it could be seen to be blaming the child and / or their carers for the problem. There is little evidence that a diet lacking in fibre is primarily responsible for causing constipation. Certainly the latest American guidelines have a statement suggesting that diet is not a major factor. There is little evidence suggesting that increasing a child's fluid intake above a reasonable amount has any effect. There is	Thank you. This will be modified in the scope. We will review evidence for effectiveness of dietary modification including fibre and fluid intake so that this UK guideline can make robust recommendations on this issue.

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				evidence to suggest that there is a genetic component. I think the point about possible Hirschsprungs is very valid.	
SH	North East Wales NHS Trust	7	3 i	The IMPACT bowel care pathway and I think Tough Going are pretty much evidence based. The problem is that there is little high quality in this field and a lot of preconceptions and prejudice. The evidence that is available is often of poor quality	Thank you. The methodology for the development of the guideline will take these two into consideration.
SH	North East Wales NHS Trust	8	4	Need to be careful in the group that are not covered: 1) What do we mean by newborns – neonates is a recognised definition 2) Why not children with a connective tissue disorder? 3) Genetic abnormalities is too exclusive, does this mean that we would not include a child with colour blindness?	Thank you. We have amended the scope to ensure consistency. The scope will cover children of all ages up to their 18th birthday and to ensure we have clearly defined the excluded groups.
SH	North East Wales NHS Trust	9	4.3	A good history is vital	Thank you. This will be addressed.
SH	North East Wales NHS Trust	10	4.3 b	Children with chronic constipation often have painful posturing not painless	Thank you. This has now been amended.
SH	North East Wales NHS Trust	11	4.3 b	Important to emphasise effects on appetite	Thank you we agree.
SH	North East Wales NHS Trust	12	4.3 b	Evidence for diet as a primary cause is poor	Thank you we agree.
SH	North East Wales NHS Trust	13	4.3 b	Need to mention effect on Daytime wetting, Nocturnal enuresis and as risk for recurrent UTI.	Thank you. We will signpost to the NICE clinical guidline on UTI in children in order to highlight these important associations.
SH	North East Wales NHS Trust	14	4.3 b	Need to think about role of school 1) Send child home? 2) Call parents in? 3) Not able to start school? 4) Facilities at school? 5) Excluded from school?	Thank you. This will be covered under the section of history-taking, management and information and support needs for families.
SH	North East Wales NHS Trust	15	4.3 c	Most care for these children is provided by nursing staff who may not be trained to undertake physical examination, is there the danger that we exclude them form caring for children with chronic	Thank you. This will be considered during GDG discussion.

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				constipation	
SH	North East Wales NHS Trust	16	4.3 c	See above for ideas about digital rectal examination	Thank you.
SH	North East Wales NHS Trust	17	4.3 d	What is the value for further investigations 1) Often performed inappropriately 2) What is their sensitivity and or specificity 3) Many nurse do not have access to these tests 4) There have been evidence based reviews to suggest that even a plain abdominal x-ray is of little value.	Thank you. Risk and benefits of investigations will be reviewed and included in the guideline.
SH	North East Wales NHS Trust	18	4.3 h	Care about emphasis on diet as a cause and also as a treatment for chronic constipation	Thank you. The role of the diet will be reviewed and considered by the GDG.
SH	North East Wales NHS Trust	19	4.3 h	Care that psychological emphasis does not mean that child are referred to psychology services at the expense of getting help from nursing/ medical staff	Thank you. The role of different interventions will be considered carefully.
SH	North East Wales NHS Trust	20	4.3 h	Care that NICE doesn't imply that children with chronic constipation NEED to be seen in secondary or even tertiary services, most can be helped in primary care, even if in reality that doesn't happen.	Thank you. Criteria for referral will be considered.
SH	North East Wales NHS Trust	21	4.3 h	Need to emphasise that good outcome depends on multidisciplinary input	Thank you.
SH	North East Wales NHS Trust	22	4.3 h	Need to look at evidence behind drug regimes and different drugs used. Often in reality outside the licence.	Thank you. These issues will be considered.
SH	North Staffordshire PCT			This organisation was approached but did not respond.	
SH	North Tees PCT			This organisation was approached but did not respond.	
SH	North Yorkshire and York PCT			This organisation was approached but did not respond.	
SH	Nottingham University Hospitals NHS Trust			This organisation was approached but did not respond.	
SH	Oldham PCT			This organisation was approached but did not respond.	
SH	Oxfordshire and Buckinghamshire Mental			This organisation was approached but did not respond.	

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	Health NHS Trust				
SH	Oxfordshire PCT			This organisation was approached but did not respond.	
SH	Paediatric Continence Forum, The			This organisation was approached but did not respond.	
SH	Pembrokeshire and Derwen NHS Trust			This organisation was approached but did not respond.	
SH	PERIGON Healthcare Ltd			This organisation was approached but did not respond.	
SH	Primary Care Society for Gastroenterology			This organisation was approached but did not respond.	
SH	PRIMIS+			This organisation was approached but did not respond.	
SH	PromoCon	1	general	This guideline is very welcomed. Constipation in childhood has been identified as amongst one of the commonest conditions in childhood … "There are a limited number of common conditions, such as constipation…, that account for a large proportion of contacts with the health service, but there are significant variations in how effectively these conditions are treated." (Getting the right start: NSF for Children Emerging findings DoH 2003)	Thank you.
SH	PromoCon	2	4.1	Exclusions There is some concern that specific groups of children may be excluded – such as those with 'special needs' Yet these are the most vulnerable and in general the least likely to receive appropriate treatment. Exclusion from NICE guidelines will increase that risk	Thank you. Children with special needs are included in the scope of the guideline. This will be clarified in the scope.
SH	PromoCon	3	4.3 c	There is in place a generally agreed consensus that rectal examination should not be carried out routinely in children over the age of 1 year as it is very distressing for the child and not necessary to diagnose constipation - See RCN publication re DRE in children and	Thank you. This will be reviewed as part of the guideline.

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				young people	
SH	PromoCon	4	4.3 d-g	I presume this relates to a guidance overview of all investigations available rather than the suggestion that children will be subjected to the whole range. In practice children with functional constipation require very little in the way of invasive tests	Thank you. Yes. The scope will be modified.
SH	PromoCon	5	4.4.1	Scope – ultimately this guideline should link in to the soon to be developed nocturnal enuresis guideline	Thank you. All NICE guidelines are cross referenced.
SH	Reckitt BenckiserHealthcare (UK) Ltd			This organisation was approached but did not respond.	
SH	Royal College of General Practitioners	1	4 c	There will be considerable debate among Primary Care Clinicians around whether DRE is an appropriate examination technique in small children with constipation. Many Doctors will perform visual inspection, looking for signs of anal fissure, soiling, perianal warts, external piles	Thank you. Issues surrounding examination will be addressed in the diagnostic section.
SH	Royal College of General Practitioners	2	4 d)	Blood investigations would not normally be undertaken in Primary Care. Phlebotomy services do not normally extend to children under 4-5 years of age. But older children usually would have investigations undertaken, often with local anaesthetic gel to minimise venepuncture discomfort.	Thank you. Service organisation issues are not covered in the scope of the guideline.
SH	Royal College of General Practitioners	3	4 f)	See RCR Guidelines MBUR6 MRI scanning departments will be seriously challenged to cope with this demand for investigation in “5% of children between 5-11” [3(b)] [around 6 million investigations over a 6-yr period?] Consideration will therefore need to be given to the value of an investigation if the wait for it then exceeds the duration of the problem itself.	Thank you. The role of the MRI will be reviewed and discussed.
SH	Royal College of General Practitioners	4	4 h)	Use of rectal preparations is becoming increasingly difficult for children in whom the carer is not the parent [children looked after by the state, and others]	Thank you. We will consider whilst making recommendations.

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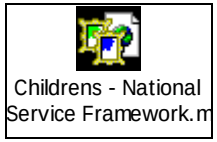
SH	Royal College of General Practitioners	5	4 i)	Consideration will need to be given to the distances involved for patients in rural area, for whom public transport would take around half a day to get to the Paediatric Gastroenterologist, and half a day back.	Thank you. The guideline will consider appropriate criteria for specialist referral.
SH	Royal College of General Practitioners	6	4 k)	There is a danger, given that these Guidelines will be for use in the National Health Service, that a holistic approach taken in the guidance, with the inclusion of Alternative Therapy Practitioners, will not be able to be applied in practice, because these practitioners cannot refer to NHS professionals, as their writ does not run.	Thank you. Service configuration will not be included but does not prevent us looking at the evidence for the service.
SH	Royal College of General Practitioners	7	General	Thank you for taking on this important piece of work, which is a problem presented to General Practitioners on a very regular basis, and for which clear guidance would be helpful.	Thank you.
SH	Royal College of Midwives			This organisation was approached but did not respond.	
SH	Royal College of Nursing	1 2	title	Suggest the title should read: Constipation: management and idiopathic constipation in children and young people in primary and secondary care.	Thank you. The remit and title have been agreed by NICE and the DOH.
SH	Royal College of Nursing	3	general	The RCN welcomes this guideline. Constipation in childhood has been identified as amongst one of the commonest conditions in childhood … "There are a limited number of common conditions, such as constipation…, that account for a large proportion of contacts with the health service, but there are significant variations in how effectively these conditions are treated." (Getting the right start: NSF for Children Emerging findings DoH 2003)	Thank you.
SH	Royal College of Nursing	4	3	It may be helpful to identify the number of GP visits and referrals to hospital and community paediatricians as well as paediatric gastroenterologists. We would like to see mentioned here about how these guidelines aim to prevent inappropriate referrals, investigations and treatments that may be distressing to the child and	Thank you for your comments. Full epidemiological review will not be undertaken but issues around criteria for referrals will be reviewed.

Status	Organisation	Order no.	Section	Comments	Responses
				their family.	
SH	Royal College of Nursing	5	3 f)	Clarity needed here: 3f) The Rome III…suggest add to sentence: ''two or fewer defecations in the toilet per week at least one episode of faecal incontinence per week after the child has acquired toileting skills…	Thank you. The definition will be discussed and clarified.
SH	Royal College of Nursing	6	4.1.1.	4.1.1 The population should cover children and young people up to their 18th birthday. Please note, as attached that the scope of the NSF Framework for Children, Young People and Maternity Services (2005) in Wales 'includes all children and young people from pre-conception to 18th birthday' The England NSF also reflects this age range.  Childrens - National Service Framework.m	Thank you. The scope will be kept in line with the NSF.
SH	Royal College of Nursing	7	4.1	Exclusions There is some concern that specific groups of children may be excluded – such as those with 'special needs' yet these are the most vulnerable and in general the least likely to receive appropriate treatment. Exclusion from NICE guidelines will increase that risk.	Thank you. Children with special needs are included in the scope of the guideline. This will be clarified in the scope.
SH	Royal College of Nursing	8	4.1.2	4.1.2 As above, we suggest that the following group should be added: d) children and young people with learning disabilities or conditions such as Attention Deficit Disorder and Autism	Thank you. These groups will be included in the scope where appropriate regarding the principles of assessment and management of their idiopathic constipation. Where there are clear differences this will not be possible. Any additional care these children may need is not covered within the scope of this guideline.
SH	Royal College of Nursing	9	4.3 b)	4.3.b Would add: 'Any medicines the child is taking, including prescribed as well as 'over the counter products' bought by parents themselves''.	Thank you. This will be covered under history taking.

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SH	Royal College of Nursing	10	4.3 c	We would suggest that somewhere in this section it should be identified that as some of these investigation will be distressing to the child or young person, they will be ordered only if absolutely clinically necessary.	Thank you. Risks and benefits of investigation will be considered.
SH	Royal College of Nursing	11	4.3 c	4.3.c: Suggest change this to : 'Physical examination may include:'	Thank you. This section will be modified.
SH	Royal College of Nursing	12	4.3 c	Also note that there is a generally agreed consensus that rectal examination should not be carried out routinely in children over the age of 1 year as it is very distressing for that child and not necessary to diagnose constipation - (RCN publication - 2005, Digital Rectal Examination (DRE) in Children and Young People, publication code- 002 062)	Thank you. Role of DRE will be considered.
SH	Royal College of Nursing	13	4.3 d-g	We presume this relates to a guidance overview of all investigations available rather than the suggestion that children will be subjected to the whole range. In practice children with functional constipation require very little in the way of invasive tests.	Thank you. Yes. The scope will be modified.
SH	Royal College of Nursing	14	4.3 d	4.3.d Suggest change this to: 'Diagnostic studies to investigate constipation may include:'	Thank you. The diagnostic tests to be reviewed will be listed but this is not to suggest all are necessary for an individual child.
SH	Royal College of Nursing	15	4.3 e	Again suggest change this to: 'Blood tests may include:'	Thank you. The particular blood tests to be considered will be decided by the GDG.
SH	Royal College of Nursing	16	4.3 f	Again suggest this to: 'Radiological investigation may include:'	Thank you. Specific radiological investigations for inclusion in the clinical question will be decided by the GDG.
SH	Royal College of Nursing	17	4.3 g	Again, suggest 'Manometry and rectal biopsy may be considered'.	Thank you. Whilst we will review the risks and benefits this does not mean they are recommended for all children.
SH	Royal College of Nursing	18	4.3 h	Again, suggest 'Management of idiopathic constipation, may include'	Thank you. The scope will be modified.
SH	Royal College of Nursing	19	4.3 l	Mention of guidelines should include perhaps clinical care pathways and algorithms to guide practice.	Thank you we agree.

Status	Organisation	Order no.	Section	Comments	Responses
SH	Royal College of Nursing	20	4.4.1	Scope – ultimately this guideline should link in to the soon to be developed nocturnal enuresis guideline	Thank you. All NICE guidelines are cross referenced.
SH	Royal College of Nursing	21	General	This is a comprehensive and informative scope.	Thank you.
SH	Royal College of Nursing	22	General	Children and young people's nurses form a large group of health professionals involved in delivering services across a broad range of settings and organisations. Our members have a lot of interest in this topic and willing to commit the time and effort needed to ensure this guideline is in place by April 2010 and help implement it.	Thank you.
SH	Royal College of Paediatrics and Child Health	1	General	Transition of care should be included in the scope. This is essential, particularly for more severe cases.	Thank you. Referral criteria will be considered.
SH	Royal College of Paediatrics and Child Health	2	General	The scope has too much emphasis on stool frequency, not enough on why constipation/stool withholding is so devastating for children and families. If the child poos once a week with no pain or discomfort and is no different before or afterwards it isn't significant. If the child passes small amounts 10 times a day and is living under a cloud of fear then it's important.	Thank you. The guideline will be patient and child focussed. The definitions will be discussed by the GDG and be clinically focussed.
SH	Royal College of Paediatrics and Child Health	3	General	Where there is a lack of evidence, we feel it is important that the guideline clearly states that any recommendations are consensus based. Advice may need to be specifically requested from stakeholders or others during consultation periods.	Thank you. The GDG interpretation of evidence which can be found in the full versions of the guideline will highlight areas which are based on evidence and those based on consensus.
SH	Royal College of Paediatrics and Child Health	4	General	The scope is appropriately wide, but seems very comprehensive in some areas and somewhat terse in others.	Thank you. The scope will be amended.
SH	Royal College of Paediatrics and Child Health	5	General	The guideline should include the importance of passing a soft easy regular stool; focusing on what comes out rather than what goes in.	Thank you for your comment.

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SH	Royal College of Paediatrics and Child Health	6	1	We believe 'diagnosis' should be mentioned in the title. We understand this point was put forward by representatives of the DH.	Thank you. This will be included.
SH	Royal College of Paediatrics and Child Health	7	3 e & f	The term 'encopresis' has not been mentioned. Currently this is used in different ways by different professional groups. For example, some use it interchangeably with 'chronic constipation and soiling'; others use it more specifically to mean 'soiling as an expression of underlying emotional problems'. We think it would be helpful to have this term clarified. 'Encopresis' may be the first indication of a significant underlying psychological problem or may be an expression of an on-going one. In this case it probably isn't truly idiopathic, but children with psychological problems are not listed under exclusions so clarification on this matter would be appreciated.	Thank you. This will be carefully defined in the glossary.
SH	Royal College of Paediatrics and Child Health	8	3 g	The scope needs to acknowledge that other organic disease (e.g. Coeliac disease) may present with apparent constipation, not only Hirschprung's disease.	Thank you. Other conditions will be discussed and considered by the GDG.
SH	Royal College of Paediatrics and Child Health	9	4.1.2	Many of the patients in this category will have functional constipation, which will often be severe. They will require similar management and care and so completely excluding them as a group is inappropriate.	Thank you. These groups of children will be included in the scope regarding the principles of assessment and management of their idiopathic constipation. Any additional care these children may need is not covered within the scope of this guideline.
SH	Royal College of Paediatrics and Child Health	10	4.1.2	Children with brain disorders will not be covered by this guideline; it is important that this is not seen as discriminating against disabled children.	Thank you. We agree and will take great care to ensure this isn't the case.
SH	Royal College of Paediatrics and Child Health	11	4 b	History-taking must include exploring with parents / carers what alternative remedies / treatments they have tried.	Thank you. We agree.
SH	Royal College of Paediatrics and Child Health	12	4.2	Tertiary care should also be included. Manometry is included is the scope and this is only available in tertiary units.	Thank you. All healthcare settings will be covered.
SH	Royal College of Paediatrics and Child Health	13	4.3	After the stakeholder meeting the College would like to emphasise the following points for inclusion	Thank you. The scope will be amended.

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				in the scope: • When does constipation need treating? • Are there steps in the treatment? E.g. changes to diet before laxatives, different types of laxatives? • What is the aim of the treatment? E.g. to treat the symptoms regardless of the dosages required or to limit the dosages for some reduction in symptoms. • What is the endpoint of treatment? How and when do we reduce laxatives? • What happens if we do not treat? • What psychological strategies have been proven to be of benefit? • When should psychological support be offered?	
SH	Royal College of Paediatrics and Child Health	14	4.3	The guideline needs to include a major focus on the impact of school; not just toilet facilities but also toilet culture. Of the children that paediatricians see who poo in school, it seems more do it in their pants than in the school toilet and the only thing children do less frequently at school than drink is to use the toilet.	Thank you we strongly agree. We suggest the college should submit a topic in this area to the centre of public health excellence at NICE for consideration.
SH	Royal College of Paediatrics and Child Health	15	4.3	History taking and physical examination should be put as sub headings under 4.3 a.	Thank you, we will address this in the scope.
SH	Royal College of Paediatrics and Child Health	16	4.3	Taking a history should hopefully obviate the need for any further investigations. The College feel that X rays, digital exam, enemata suppositories are all procedures that should be undertaken rarely.	Yes, we agree.
SH	Royal College of Paediatrics and Child Health	17	4.3	We would appreciate a clearer explanation of 'cultural considerations'.	Thank you. There is a wide range of considerations that will be discussed by GDG.
SH	Royal College of Paediatrics and Child Health	18	4.3 c	Physical examination should include investigation of: • Faeces • Developmental appropriateness • Skin condition e.g. dryness, rash.	Thank you. Contributory factors will be considered.
SH	Royal College of Paediatrics	19	4.3 c	The investigation of the abdomen should describe	Thank you. Contributory factors will be

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	and Child Health			looking for distension, palpable mass, indentability of mass, tenderness, perianal sensation etc.	considered.
SH	Royal College of Paediatrics and Child Health	20	4.3 c	Rectal examinations are distressing for the child and should not be done routinely. Rather they should be reserved for where problems are expected.	Thank you. Role of DRE will be the subject of a systematic review and considered by the GDG.
SH	Royal College of Paediatrics and Child Health	21	4.3 e	In this section we feel the role of tests for cow's milk protein allergy should be discussed.	Sorry, but this remains outside the scope of this guideline.
SH	Royal College of Paediatrics and Child Health	22	4.3 e	With anti TTG to exclude celiac disease, IgA antibodies should be done to exclude false negative test.	Sorry, but this remains outside the scope of this guideline.
SH	Royal College of Paediatrics and Child Health	23	4.3 e, f & g	We believe that sections e, f and g should be sub-heading of 4.3 d. Blood tests should only be conducted in selected cases.	Thank you. The scope will be modified.
SH	Royal College of Paediatrics and Child Health	24	4.3 f	Radiological investigations should be recommended in selected cases only.	Thank you. The risk and benefits will be considered fully.
SH	Royal College of Paediatrics and Child Health	25	4.3 g	Manometry should be conducted in selected tertiary centres for non-responders, and rectal biopsy should be done only if there is suspected Hirschsprung's Disease with meconium not passed in the first 24 hours.	Thank you. The risk and benefits will be considered.
SH	Royal College of Paediatrics and Child Health	26	4.3 h	We would like the guideline to include advice about how long pharmacological treatment should be continued and how it should be weaned.	Thank you we agree. This will be included in the GDG discussion.
SH	Royal College of Paediatrics and Child Health	27	4.3 h	Surgical approaches have not been defined explicitly, e.g. ACE and Pouch procedures. These procedures are controversial in parts of the UK and without explicitly mentioning them some of the evidence on their use may be missed. Furthermore, procedures such as ACE are only available in tertiary care which should be mentioned in the healthcare settings section (4.2).	Thank you. Risk and benefits of surgical intervention will be reviewed.
SH	Royal College of Paediatrics and Child Health	28	4.3 h	We feel the term 'pharmacological intervention' is misleading; opiates can cause worsening of constipation and should not be used, antispasmodics can have a similar effect by causing the slowing of peristalsis.	Thank you. Risk and benefits of pharmacological interventions relevant to idiopathic constipation will be considered.
SH	Royal College of Paediatrics and Child Health	29	4.3 h	We would like to see some details of common laxatives and their mechanism of action/dosages given. It should also be mentioned that children	Thank you. Risk and benefits of pharmacological interventions relevant to idiopathic constipation will be considered.

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				may need varying doses of laxatives which may be even larger than adult doses.	
SH	Royal College of Paediatrics and Child Health	30	4.3 h	Intense (psychodynamic) psychotherapy is a specific highly skilled discipline rather than a form of psychosocial counselling.	Thank you. Definitions will be discussed by the GDG and included in the full guideline.
SH	Royal College of Paediatrics and Child Health	31	4.3 i	It would be helpful to see a definition of secondary referral; some children may have had a secondary referral to a surgeon and never been offered a senior paediatric medical approach.	Thank you. Criteria for referral will be considered.
SH	Royal College of Paediatrics and Child Health	32	4.3 i	Some guidance around referral to a paediatrician with expertise in children's mental health, or to CAMHS, would be appropriate, e.g. with soiling in inappropriate places, smearing, etc. It is also very important to remember that many children with longstanding constipation, often with soiling, readily develop secondary psychological problems. Therefore, dedicated constipation clinics are best run jointly with a mental health professional such as a paediatric psychologist .	Thank you. Criteria for referral will be considered.
SH	Royal College of Pathologists			This organisation was approached but did not respond.	
SH	Royal College of Radiologists			This organisation was approached but did not respond.	
SH	Royal Society of Medicine			This organisation was approached but did not respond.	
SH	SACAR			This organisation was approached but did not respond.	
SH	Sandwell PCT			This organisation was approached but did not respond.	
SH	SCHOOL AND PUBLIC HEALTH NURSES ASSOCIATION			This organisation was approached but did not respond.	
SH	Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached but did not respond.	
SH	Scottish Nutrition & Diet Resources Initiative			This organisation was approached but did not respond.	
SH	Sedgefield PCT			This organisation was approached but did not respond.	
SH	Sheffield Children's NHS Foundation Trust			This organisation was approached but did not respond.	

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SH	Sheffield PCT			This organisation was approached but did not respond.	
SH	Sheffield Teaching Hospitals NHS Foundation Trust	1	4.1.1	Upper age limit probably best to be the same as agreed for the nocturnal enuresis guideline – not sure if this will be 16 or 18. NSF for Children uses 18 years as upper limit	Thank you. The scope will be kept in line with the NSF.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	2	4.1.2	There are a lot of exclusions here. Surely it would be sensible to include (not necessarily by name) those conditions which are associated with a tendency to constipation – eg Downs syndrome, Mild CP, etc where the management **is going to be the same.** It should definitely include children with autistic spectrum disorders who have an increased incidence of constipation / soiling and withholding behaviours. I would consider rewording the whole of this section.	Thank you. These groups of children will be included in the scope regarding the principles of assessment and management of their idiopathic constipation. Any additional care these children may need is not covered within the scope of this guideline.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	3	4.1.2	Will it include those children with learning difficulties and delay in developing toileting – who may have soiling with or without constipation often with delay in becoming dry day and night as well. This might be a good group to specifically exclude as the management may be significantly different. However this group does contain children managed in nappies where constipation has not been recognised and the resulting soiling has become the reason for the delay in developing toileting.	Thank you. These groups of children will be included in the guideline.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	4	4.2	Does this need to specifically include “continence services”?	Thank you. All healthcare settings will be covered.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	5	4.3 b	History should specify difference between time of successful toilet training for stools and for urine as may be significantly different	Thank you. A section in the guideline will be included that covers history taking.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	6	4.3 c	Physical examination does NOT need to include digital rectal examination	Thank you. Role of DRE will be the subject of a systematic review and considered by the GDG.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	7	4.3 e and f	I hope some items on these lists will be optional or will never see the light of day in the finished guideline! However it should also include rectal / abdominal ultrasound	Thank you. The risks benefits of the tests will be considered.

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SH	Sheffield Teaching Hospitals NHS Foundation Trust	8	4.3 h	Maybe add in Tens therapy (Stimulating S3 in the leg to encourage better rectal sensation)	Thank you. The risks and benefits of these procedures will be considered.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	9	4.3 h	Under surgical management - the ACE procedure and maybe also Botox injections around the anal sphincter	Thank you. The risks and benefits of these procedures will be considered.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	10	4.3 h	I really don't like to see analgesia mentioned at all except possibly for local anaesthetic in the anal region. Rarely needed in children	Thank you. We agree but the risks and benefits of procedures and therapies will be considered by the GDG.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	11	4.3 i	It would be helpful to indicate – maybe in the implementation - the usefulness of an integrated continence service and the role of paediatric continence nurse advisors / specialists. They have a major role to play in supporting children with these conditions, with support from an appropriate paediatrician. Gastroenterology referrals should rarely be needed for children with functional constipation/soiling.	Thank you. Criteria for referral will be considered.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	12	General	Should the guideline contain some advice for school staff on the appropriate action they should take for a child who is soiling in school – ie not to just ignore it!	Thank you. Advice will be provided for all health care professionals looking after children.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	13	4.3 j	Information leaflets to include school staff please	Thank you we agree.
SH	Sheffield Teaching Hospitals NHS Foundation Trust	14	General	Could you change the title of the guideline to read just "Childhood Constipation Guideline". Idiopathic means very little – and probably doesn't exist. "Functional" could be a more acceptable term if you need a qualifier.	Thank you. The remit and title have been agreed by NICE and the DOH.
SH	Social Care Institute for Excellence (SCIE)			This organisation was approached but did not respond.	
SH	Southampton City PCT	1	3 a	I have found the clinical need for the guideline to be misleading in some paragraphs. Constipation is a difficulty or delay in the passing of stools leading to distress. Infrequent cannot be defined as some people may go easily every 2-3 days. To quantify the timing and passage of stools is impossible per individual. 99.2% of healthy newborn babies will pass meconium within 48	Thank you. The definition of constipation will be discussed by the GDG and presented in the final guideline. We are aware of the various existing definitions including Rome 111.

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				hours of birth. 98.3% of infants aged 6 weeks (either breast milk and formula milk fed) pass stool within the range 3 times a day or more, to once every 3 days. This means bowel frequency of less than every 3 days is unusual in this age group. 85% of primary school children pass stools once or twice a day, and 96% do so three times daily to once every other day. This means a bowel frequency of less than every 3 days is unusual in this age group. (stats obtained from Assessment and management of idiopathic constipation and soiling: Guidelines. Dr C Phillips, Dr R. M. Beattie, Mr M Griffiths) So't'on Univ Hosp Trust.	
SH	Southampton City PCT	2	3 a	The explanation in 3 a, does not explain the normal variants of children' normal passing of stool adequately.	Thank you. This will be addressed within the guideline where constipation will be defined.
SH	Southampton City PCT	3	3 b	Is a source of considerable anxiety and disruption to family function.	Thank you we agree.
SH	Southampton City PCT	4	3 b	Chronic constipation generally develops between the ages of 1 and 4 years and can be cyclic or intractable. It can also occur at any other age.	Thank you. Definitions will be addressed by the GDG.
SH	Southampton City PCT	5	3 b	Constipation can continue beyond puberty generally improving for males and becoming problematic in females particularly when menstruation commences.	Thank you we agree. Definitions will be addressed by the GDG.
SH	Southampton City PCT	6	3 c	Parent often do not seek help because they do not understand what the problem is and are unable to identify with it. They feel inadequate as parents. They often think their child is wilfully playing them up. They believe there is some underlying psychological problem. When they do seek help, they are often not taken seriously, or there is no service provision to advise them.	Thank you. This will be included in the 'Understanding NICE guidance' which is a publication for the general public. We hope that producing a NICE guideline on this topic will help to underline that it is indeed a condition that needs to be taken seriously by health care professionals.
SH	Southampton City PCT	7	3 d	Faecal retention causes the fissures in the anus during the passing of mega stools. Not the other way round.	Thank you, details of faecal retention and anal fissures have now been removed from the background section of the scope.
SH	Southampton City PCT	8	3 d	Bleeding will happen as a consequence.	Thank you for your comment. This has now been removed from the background section of the scope.

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SH	Southampton City PCT	9	3 d	Further defecation will be painful and cause further bleeding, leading to stool holding.	Thank you. This has now been removed from the scope.
SH	Southampton City PCT	10	3 d	Incontinence of faeces is soiling due to faecal loading.	Thank you. This will be reflected in the updated scope.
SH	Southampton City PCT	11	3 d	Incontinence of urine would be secondary to holding on to urine to prevent defecation. This is unusual.	Thank you for highlighting this issue.
SH	Southampton City PCT	12	3 d	Soiling is mostly due to overflow	Thank you we agree.
SH	Southampton City PCT	13	3 d	Vomiting generally occurs when the child is severely faecally impacted.	Thank you for your comment.
SH	Southampton City PCT	14	3 d	Depression, social withdrawal etc are secondary to feeling unwell and under performing plus low self esteem due to soiling and not being able to control their own bodily function.	Thank you for your comment. Issues surrounding psychosocial wellbeing and quality of life will be considered as outcomes where evidence allows.
SH	Southampton City PCT	15	3 e	Constipation need not last 2 weeks or more to be a problem. It can last 2 days and be 'constipation' and 'a problem'. It can then be alleviated by defecation but can return in 1 to 2 weeks giving cyclic or more constant problems.	Thank you for your comment.
SH	Southampton City PCT	16	3 h	The majority of children with constipation are seen by Health Visitors, children's community health nurses and school nurses. Those who do not respond to first line advice are referred to the GP.	Thank you. We agree. The guideline is aimed at all health care professionals managing these children.
SH	Southampton City PCT	17	4.1.2 e	I would query the need to exclude this group.	Thank you. This section has been reworded to afford greater clarity regarding exclusions.
SH	Southampton City PCT	18	4.3 b	Home toilet facilities. No: of toilets. Seating on toilet. Step. Training seat. Availability especially in the morning.	Thank you. This will be covered in a section in the guideline on history taking.
SH	Southampton City PCT	19	4.3 b	Parental, sibling and peer reactions to soiling.	Thank you. This will be discussed by the GDG.
SH	Southampton City PCT	20	4.3 b	Ability to change clothing, and appropriately place soiled clothing for laundry. Privacy to do so.	Thank you. This will be discussed by GDG.
SH	Southampton City PCT	21	4.3 h	Shouldn't be necessary to exclude cows milk protein. This should be assessed individually and probably with medical evidence.	Thank you we agree.
SH	Southampton City PCT	22	4.3 h	I have never used, or known any professional to advocate the use of mineral oils. Osmotic medicines are used.	Thank you. The risks and benefits of different therapies will be discussed by the GDG.

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SH	Southampton City PCT	23	4.3 h	I have never found a use for analgesia in constipation, particularly opiates. If abdominal pain is suffered then a poo is required either willingly or by the administration of rectal enema or suppositories dependant on age and degree of constipation.	Thank you we agree. The risks and benefits of different therapies will be discussed by the GDG.
SH	Southampton City PCT	24	4.3 k	Complementary and alternative approaches serve to make parents feel empowered to help their child. Constipation is functional. They would be better served by changing their diets, toileting routine and lifestyle.	Thank you for your comments.
SH	Southampton University Hospital NHS Trust			This organisation was approached but did not respond.	
SH	The British Dietetic Association			This organisation was approached but did not respond.	
SH	The British Psychological Society			This organisation was approached but did not respond.	
SH	The Chartered Society of Physiotherapy			This organisation was approached but did not respond.	
SH	The Royal West Sussex Trust	1	Title	Suggest using Rome III Pediatric term Functional Constipation: see also 4.3a	Thank you. The remit and title have been agreed by NICE and the DOH.
SH	The Royal West Sussex Trust	2	4.3 b	The use of the term 'soiling' should be avoided as it can be used interchangeably with encopresis. Is 'painless posturing' retentive posturing? Dietary history should include relationship of dietary changes (cessation of breast feeding, introduction of solids) with onset of symptoms.	Thank you. Definitions and their relevance to the management of constipation will be discussed and considered by the GDG. A section in the guideline will be included that covers history taking.
SH	The Royal West Sussex Trust	3	4.3 c	Guidelines are required on the indication for and timing of rectal examination. For example, should rectal examination be performed in children in primary care? Does 'peripheral nervous system' refer to the lower limbs?	Thank you. Role of DRE will be the subject of a systematic review and considered by the GDG.
SH	The Royal West Sussex Trust	4	4.3 h	The Guideline Group should review the evidence for pharmacological interventions for maintenance treatments separately from disimpaction. Anti-allergy pharmacological interventions and exclusion diets for those who fail maintenance treatment. Role of Probiotics. Surgical management should also include antegrade colonic enema (ACE) and alternative procedures.	Thank you. The role of different interventions will be discussed by the GDG.

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SH	University College Hospital London NHS Foundation Trust			This organisation was approached but did not respond.	
SH	University College Londons Hospitals NHS Foundation Trust			This organisation was approached but did not respond.	
SH	Vygon (UK) Ltd			This organisation was approached but did not respond.	
SH	Weight Concern			This organisation was approached but did not respond.	
SH	Welsh Assembly Government			This organisation was approached but did not respond.	
SH	Welsh Scientific Advisory Committee (WSAC)			This organisation was approached but did not respond.	
SH	West & East & North Hertfordshire PCTs			This organisation was approached but did not respond.	
SH	Winchester and Eastleigh Healthcare Trust			This organisation was approached but did not respond.	
SH	Yeovil District Hospital Constipation Service	1	4.1.2	Suggest that this be simplified to “Patients with underlying conditions known to be associated with disordered bowel function, including: structural gut abnormalities and neurological disorders”	Thank you. This section has now been amended to afford greater clarity.
SH	Yeovil District Hospital Constipation Service	2	4.3	Suggest opening statement along the lines of “Patients with idiopathic constipation do not have features suggestive of organic or structural pathology. Organic & structural causes can be excluded by details of history, findings on examination and occasionally by specific investigations. History suggestive of organic causes include”….” Physical findings suggestive of organic causes include “…” Investigations needed to exclude underlying organic causes include “…”	Thank you. Definitions and their relevance to the management of constipation will be discussed and considered by the GDG.

Status	Organisation	Order no.	Section	Comments	Responses
SH	Yeovil District Hospital Constipation Service	3	4.3 e)	Suggest “serological testing for coeliac disease” rather than “tissue transglutaminase antibodies” as this test is not always available and something new may replace it	Sorry, this is outside the remit of the scope.
SH	Yeovil District Hospital Constipation Service	4	4.3 h)	Management needs its own section as this is the “meat” of the whole exercise, and the one that practitioners are most likely to use	Thank you we agree. The scope will be modified.
SH	Yeovil District Hospital Constipation Service	5	4.3 h)	Surgical management is always going to be a tertiary intervention and so doesn’t fall within the remit of this document	Thank you. The remit has been expanded to include tertiary care and will be reflected in the scope.
SH	Yeovil District Hospital Constipation Service	6	4.3 i)	Indications for referral ought to be a separate section	Thank you. This will be a subsection of clinical management.
SH	Yeovil District Hospital Constipation Service	7	4.3 k, l)	We wonder whether it is worthwhile spending much time on ineffectual interventions, as presumably the list is infinite. One imagine that practitioners are interested primarily in interventions that actually work.	Thank you. Risk benefits of interventions will be considered.
SH	York Hospital NHS Trust			This organisation was approached but did not respond.	