NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Constipation in children and young people

Date of Quality Standards Advisory Committee post-consultation meeting:
6th February 2014

2 Introduction

The draft quality standard for Constipation in children and young people was made available on the NICE website for a 4-week public consultation period between 10th December 2013 and 14th January 2014. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 13 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include overarching outcomes, thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?

Stakeholders were also invited to respond to the following statement specific questions:

1. For draft quality statement 3: Is one review type often carried out better than the other or do both types of treatment review need equal levels of improvement?

2. For draft quality statement 4: What is the most important piece of information that should be provided as part of a written personalised management plan?

3. For draft quality statement 5: Is it clear what ‘respond to initial treatment’ means?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- General support for the draft quality statements on constipation in children and young people.
- Some concern that the quality standard adds layers of complexity that may prevent effective primary care management.
- General comments about a lack of properly commissioned integrated paediatric continence services to ensure care is not fragmented and reduce emergency admissions to secondary care.
- The importance of the role of pharmacists in assessing, referring and treating children and young people with constipation was highlighted.
- Stakeholders suggested the need to highlight pathways of care for constipation in each locality that incorporates each of the statements.

Consultation comments on data collection

- Some stakeholders felt that data collection is possible if the systems and structures are available
- Better capture of referrals needed to analyse activity
- Query regarding the usefulness of A&E attendance and unplanned admissions as an outcome measure because children with a poor response to initial treatment remain in the community or are often see as an outpatient
- Some stakeholders questioned the practicality of data collection
- Quality of a personalised plan would be difficult to capture and further guidance on the content and how to keep a record of it needed
- Suggestion for a template for constipation on electronic systems to aid data collection and use of Read codes

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Children and young people with constipation receive a full assessment before a diagnosis of idiopathic constipation is made.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- Concerns were raised that the emphasis on a “full assessment” might deter staff in primary care from completing it due to time limitations or lack of confidence in their skills, which could lead to increased referrals to secondary care and delays in treatment.
- Stakeholders highlighted the importance of staff knowledge and training.
- Stakeholders suggested there should be clarity about where the assessment should take place and which service providers should do it.
- Stakeholders felt that the initial assessment should take place in primary care or a community setting and should be part of a pathway for subsequent care. Local pathways should involve health visitors, community nursing staff and GPs.
- Stakeholders suggested that the quality standard should encourage community clinics for children with toileting problems.
- The suggested outcome of A+E attendance rates will not inform commissioners if assessments are being done.

5.2 Draft statement 2

Children and young people with idiopathic constipation receive oral macrogols as first-line treatment.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Stakeholders suggested that other laxatives, such as Senna, sodium picosulphate and Lactulose, are as acceptable as macrogols, less aggressive and suitable for children under 5.
- The role of maintenance treatment should be mentioned in the statement, i.e. as part of the treatment package at the same time as commencing first-line treatment to avoid health professionals placing too much emphasis on this statement.
- The lack of detail on doses was highlighted as well as GPs’ reluctance to prescribe high doses and the tendency of parents to reduce doses or discontinue treatment.

- Suppositories were suggested for use in aiding initial disimpaction.
- Stakeholders felt that it is unclear whether this is being done and suggested that local leadership is needed to promote this as best practice.

5.3 Draft statement 3

Children and young people with idiopathic constipation undergoing laxative treatment have their treatment reviewed by a healthcare professional.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- Concerns were raised that this statement assumes that children are better after disimpaction and need no further input.
- Stakeholders suggested that the statement should be amended to state that the healthcare professional must be “appropriately trained”.
- The use of the word ‘blockage’ seems inappropriate and supports the impression that the statement is aimed at inexperienced professionals.
- Timeframe: 6 weeks was felt to be too long to wait for review following the first review for disimpaction and from initiation of maintenance treatment.
- Timeframe: It is not clear when disimpaction treatment should be reviewed again after the first review within 1 week.
- The statement needs to be more clearly worded to make an impact.
- Commissioners need to address the practicalities of delivering this as school nurses, health visitors and practice nurses are not trained or in a position to manage this.
- Continuity of care is important and the child and family should be seen by the same health professionals and given the same messages throughout.
- There should be a clear point of professional contact or use of telephone contact for children and young people with idiopathic constipation and their families.
- The standard should mention having a lead professional who can advise colleagues on individual cases.

Consultation question 3

Stakeholders made the following comments in relation to consultation question 3:

- Some stakeholders thought that both types of treatment review need improvement.
- Other stakeholders thought that the 1 week review for disimpaction treatment is carried out less well and needs more emphasis.

5.4 Draft statement 4

Children and young people with idiopathic constipation undergoing laxative treatment receive a written personalised management plan.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- Concerns were raised that staff in care settings will not have sufficient time to write a personalised plan for every child.
- The use of published literature or signposting to generic advice on the NICE website was suggested as an alternative option to the personalised plan.
- A template for a written fact sheet or pre-prepared generic information that can be easily personalised could be developed. Stakeholders also emphasised the role of a professional point of contact as well as professional advice by telephone during the initial management phase.
- Stakeholders recommended that any plan should reflect the details in NICE clinical guideline 99.

Consultation question 4

Stakeholders made the following comments in relation to consultation question 4:

- How and when to contact the local provider is important.
- Signposting to generic advice on the NICE website.
- Information needs to be clear and client focussed.
- Suggestions of the most important information to include were:

  - dose adjustment: how to decide whether to make adjustments in light of response and what adjustments to make
  - when to seek review
  - the importance of continuing treatment until advised to stop by a healthcare professional
  - what to expect when taking laxatives e.g. things might get worse initially
  - how to avoid a recurrence in future and recognise risk situations for relapse
  - lifestyle advice
  - the diagnosis process
  - how to take their medication
  - how bowels work, how to poo and the origins of constipation
  - symptoms that might indicate a serious underlying problem

5.5 Draft statement 5

Children and young people with idiopathic constipation who do not respond to initial treatment within 3 months are referred to a specialist.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- Stakeholders suggested that “specialist” should be defined as
  - A “paediatrician” to prevent tertiary gastroenterology services being swamped by inappropriate constipation referrals
  - Professionals within community-based paediatric services
- Children and young people need to be reviewed by a GP before being referred on.
- Health professionals need to determine whether the treatment plan has been adhered to, i.e. whether medication was taken, prior to referral.
- Stakeholders suggested that primary health care professionals should remain involved in the care of the child or young person after referral and questioned how specialists should work with them to optimise management.
- Stakeholders questioned who the “specialists” are and what their role is.
- A lead continence nurse to guide and advise other professionals was recommended as a better use of resources.

Consultation question 5

Stakeholders made the following comments in relation to consultation question 5:

- Some stakeholders thought that it is clear what ‘respond to initial treatment’ means.
- Other stakeholders thought that it was not clear and wanted further clarification.
- Suggestions of how to clarify *‘respond to initial treatment’* include:
  - no significant progress as judged by either the health professional or the parents (and child)
  - use of the Bristol Stool form scale e.g. the number of type 4 stools per week
  - improvement in symptoms but not necessarily weaning and discontinuation of laxative treatment. Symptom free treatment over the time frame specified is considered successful treatment

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Families (especially parents) to be supported in managing their child’s constipation.

Appendix 1: Quality standard consultation comments table

ID	Stakeholder	Statement no	Comments
1	British Society of Paediatric Gastroenterology & Nutrition	General	Thank you for allowing us to comment. Our organisation like to express an interest in endorsing this quality standard
2	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
3	NHS England	General	Thank you for the opportunity to comment on the engagement exercise for the above quality standard I wish to confirm that NHS England has no substantive comments to make regarding this consultation.
4	Paediatric Continence Forum	General	The Paediatric Continence Forum (PCF) welcomes the development of this quality standard for constipation in children and young people, which we hope we help address the significant challenges of supporting those children and young people concerned. As the NICE guideline indicates, between 5% and 30% of children and young people are affected, and it is more common amongst those with physical disabilities. The PCF is a national group of patient representatives and healthcare professionals which campaigns for improved services for children with continence problems. It was established in 2003, and works closely with the national charities ERIC (Education and Resources for Improving Childhood Continence) and PromoCon (Promoting Continence through Product Awareness). One of the key goals of the PCF is for every area in the UK to have a proper community-based integrated paediatric continence treatment service, led by an expert paediatric continence professional, with a clear system of referral and care pathways across primary and secondary NHS care, education and social services. There is evidence that clinical outcomes are higher when a service is integrated (Royal College of Physicians National Audit of Continence Care 2010). NICE states that an effective, integrated paediatric continence service could lead to up to an 80% reduction in the number of emergency admissions to secondary care (NICE Commissioning Guide 2010). Emergency admissions for constipation in England are currently being measured by CHIMAT.
5	Paediatric Continence Forum	General	The PCF would like to reiterate that continence problems occur at a formative time for children, which influence their health, wellbeing, and emotional development. There is evidence that they are associated with emotional and behavioural problems, including a strong association with bullying, both as recipients and perpetrators. Continence problem, including constipation, can also reduce self-esteem at a crucial time during a child’s emotional development, risking their exclusion from normal social interaction (e.g. school trips or sleepovers).

ID	Stakeholder	Statement no	Comments
6	Paediatric Continence Forum	General	In response to evidence that paediatric continence services are not being properly commissioned, the PCF has written a Commissioning Guide for Paediatric Continence, which is currently being considered for accreditation by NICE.
7	Royal College of Nursing	General	There is a lack of integrated paediatric continence services to ensure care is not fragmented, many children suffer for years and are rarely referred as quickly as this document suggests. So we would welcome its application.
8	Royal College of Paediatrics and Child Health	General	It would be helpful if this standard could also state that there should be a pathway of care for constipation in each locality that incorporates each of the statements. This should facilitate achieving this standard.
9	Royal College of Paediatrics and Child Health	General	An additional statement would be helpful to require families (especially parents), to be supported in managing their child’s constipation. It might be assumed that this would be the case, although this has not always been the experience of parent carers.
10	Royal Pharmaceutical Society	General	The Royal Pharmaceutical Society welcomes the quality standard for constipation in children and young people and agrees with the draft quality statements.
11	Welsh Government	General	**In Summary** I think serious re-drafting and a different emphasis is required as this QS has very little in common with the spirit and direction of the original guideline. It is adding layers of unnecessary complexity which will simply drive the problem away for effective primary care management.
12	Central Manchester Foundation Trust	Question 1	I feel the draft quality standards does accurately reflect the key areas for quality improvement
13	Leeds Teaching Hospitals NHS Trust	Question 1	Yes I think this draft quality standard accurately reflects the key areas for quality improvement
14	Paediatric Continence Forum	Question 1	PCF agrees that this draft quality standard accurately reflects the key areas for quality improvement.
15	Rotherham Doncaster and South Humber NHS Foundation Trust	Question 1	Yes the draft does reflect the key areas for improvement
16	Royal College of Surgeons Edinburgh	Question 1	The Royal College of Surgeons of Edinburgh (RCSEd) believes that the standards suggested are reasonable and reflect areas for improvement both in primary and secondary care. The standards appear to be fully consistent with both NICE and local guidance.
17	Central Manchester Foundation Trust	Question 2	Yes this could be possible although need for better documentation regarding referrals in order to get the necessary information
18	Leeds Teaching Hospitals NHS Trust	Question 2	If the systems and structures were available, I think it would be possible to collect the data for the proposed quality measures since they are all measurable outcomes.

ID	Stakeholder	Statement no	Comments
19	Rotherham Doncaster and South Humber NHS Foundation Trust	Question 2	This may be difficult, relies on read codes being used to allow for easy audit, there is no template on electronic systems for constipation – this would make audit much easier and allow collection of the data of the proposed quality measures. Relating to medication – this should be relatively easy to collect data relating to first line treatment. Review – again use of read codes would allow data collection to assess this as would template with review area. Personalised plan – could evaluate with clients/carers, the quality of the plan would be more difficult to assess without further guidelines been given to the content and how this is recorded in client records what information has been agreed and given.
20	Royal College of Surgeons Edinburgh	Question 2	The College would have doubts about the practicality of collecting information, particularly in relation to standards 1, 3, 4 and 5. The College also doubts the usefulness of A&E attendance and unplanned admissions as a sensitive outcome measure. The majority of patients with a poor response to initial treatment continue in the community without hospital contact until a late referral to OP clinics. Subsequent treatment for the vast majority remains OP based with most admissions being on an elective rather than emergency basis.
21	British Society of Paediatric Gastroenterology & Nutrition	Statement 1	These QS should make management of constipation easier and facilitate early and effective care in primary care and in the community. The QS may not be in keeping with the spirit and direction of the original guideline, as these QS may be adding layers of unnecessary complexity which could prevent effective primary care management and even reverse some of the progress that has been achieved in the successful treatment of this very common condition.
			The QS should be clear where the assessment should take place and give guidance on which service providers should initially do it and perhaps give suggestions of local arrangements that are effective.
			The QS should be clear that the initial assessment should be in primary care or in the community setting and be part of a pathway for subsequent care. The emphasis on a “Full Assessment” may deter medical and /or nursing (health visitor, HV, school nurse, or practice nurse or community nurse) colleagues in primary care, since current arrangements allow only 5 – 10 minutes to see patients.

ID	Stakeholder	Statement no	Comments
			The risk is that Instead of undertaking an assessment, a GP or HV may refer the child to secondary care if they do not feel skilled or confident to make a full assessment on a child. Alternatively, the families may be moved towards A and E departments to have an assessment by a children's doctor. By the time the children are seen in secondary care, the problem may be protracted or have become more complicated because of a delay in receiving the correct diagnosis, advice and treatment. Structure Evidence of the "local arrangements" is not described. While these will vary depending upon locality and resources, it is more helpful to state that clear local pathways should be developed that involve health visitors, community nursing staff and GP's in order that they feel confident and have the necessary time and training and structure to assess children with constipation. The implementation of such pathways will require engagement of and necessary up skilling of GP's and community nursing staff, so that they are confident to undertake the assessment in primary care of in the community and continue care in community clinics for example... It is such a common problem, that QS should encourage community clinics for children with toileting problems which are cost effective. There would be an emphasis on early diagnosis and prevention of chronic constipation, which is a frequent sequel in children who have had an incomplete assessment and inadequate management of short term constipation.
22	Royal College of Paediatrics and Child Health	Statement 1	Assessment assumes knowledge and/ training: what are the standards re this? a. in primary care b. paediatric services. How would Commissioners know if this was being done as the baseline is not known and A and E attendance w problems does not answer this?
23	Royal College of Surgeons Edinburgh	Statement 1	Digital rectal examination should be the exception not, as implied, the norm. The knowledge of "normal" amongst children by many healthcare professionals may not be expert enough to justify them doing this examination as a rule. Perianal inspection is important and will pick up most abnormalities except the very rare.
24	Royal Pharmaceutical Society	Statement 1	Children and young people with constipation will often present first to a community pharmacist because the accessible and inviting environment of community pharmacies allows patients to seek advice and have conversations about their (and their children's) symptoms at a time that is convenient for them, without having to make an appointment. A wide range of pharmacy (P) medicines to treat constipation are available and pharmacists have an important role in identifying children and young people who are constipated and ensuring that they are referred for diagnosis at an early stage.
25	Welsh Government	Statement 1	The emphasis on "Full Assessment" will almost certainly put off colleagues in primary care who have between 5 – 10 minutes to see patients. Instead they will refer to secondary care. By the time the children are seen the problem will have become more complicated because of a needless delay in receiving the correct advice and

ID	Stakeholder	Statement no	Comments
			treatment
26	British Society of Paediatric Gastroenterology & Nutrition	Statement 2	The NICE Guideline was effective in that it emphasized the need for early aggressive laxative treatment using sufficient macrogols for long enough and emphasized that first line treatment is only the start of an effective care pathway. The CG also gave guidance on other laxatives that may be required if children do not suit macrogols. The statement in the QS is too didactic. There will be situations where other laxatives like Senna or sodium picosulphate would be as acceptable as Macrogols and the QS should acknowledge this. There is no mention of maintenance treatment which must be considered early on to prevent recurrence. This should be alluded to as part of the treatment package at the same time as commencing first-line treatment to avoid health professionals placing too much emphasis on this statement in the quality standard.
27	NHS Direct	Statement 2	There are no suggested amounts of macrogols to be used. Since initial management is in a primary care setting, perhaps NICE should be more prescriptive about this. However, probably this would be addressed in full publication. From General Practice personal experience some GPs are reluctant to prescribe the apparently large amounts of laxatives required. Parents are often quick to reduce doses or discontinue treatment, leading to incomplete/failed treatment and recurrence of symptoms
28	Royal College of Paediatrics and Child Health	Statement 2	Similar response as above but we agree that this could be promoted as best practice advice – whether / not taken up not clear. Needs local leadership?
29	Royal College of Surgeons Edinburgh	Statement 2	The College is concerned with the use of Macrogols as first line treatment. This is very aggressive and is prescribing off licence in children under five. The majority of constipated children respond to adequate doses of Lactulose and Senna. This is both more cost efficient and within the drug licence. It may be irresponsible to recommend a regime that requires off licence prescribing for most children to whom it will apply. The College questions whether there is any level 1 evidence to support this?

ID	Stakeholder	Statement no	Comments
			There is no mention in the management section of suppositories. These can be very useful in aiding the initial disimpaction and relieving distress caused by severe constipation and inability to pass a stool.
30	Royal Pharmaceutical Society	Statement 2	As experts in medicines, pharmacists carry out a clinical check of prescribed medicines and will therefore have an important role in ensuring that children and young people with idiopathic constipation receive the recommended first–line treatment.
31	British Society of Paediatric Gastroenterology & Nutrition	Statement 3	All children receiving treatments for any condition should be reviewed by a health care professional to determine if the treatment has been effective and plan the next phase of treatment. The quality statement should state this. This Statement assumes that children may often be better after disimpaction treatment and need no further input
32	Paediatric Continence Forum	Statement 3	PCF believes this quality statement should be amended to state that the healthcare professional must be “appropriately trained”, by which PCF means a healthcare professional, trained in paediatrics, who has a good level of understanding of the range of continence issues. Such an individual should be able to fully understand the implications of constipation/soiling on an individual’s health and wellbeing, and manage the situation with the appropriate sensitivity and empathy.
33	Royal College of Nursing	Statement 3	Most important is the continuity of care so the child and family is seen by same health professionals and the same message given as treatment can last for 12 months or more.
34	Royal College of Paediatrics and Child Health	Statement 3	Reviewing is a major issue and question and lack of reviews and guidance contribute significantly to failed management. It is problematic to leave the guidance so wide when it is guidance on best practice presumably for professionals who have less experience? 1. Agree Disimpaction clearly needs early review and then …? Sooner than ‘within 6 weeks’ follow up 2. We understand the difficulties but < 6 weeks is a long time if this is new treatment, even if flexible and individualised in the Standard, [although better than many Drs seem to offer!] Needs a more clearly worded Standard or may not make much impact. 3. NICE guidance rightly emphasises having a clear point of professional contact, use of telephone contact and the importance of basic guidance on not reducing / see sawing doses. 4. We are not aware that most School nurses or even most HVs or practice nurses are generally trained or in a position to manage this – so commissioners would need to address the practicalities. 5. The NICE data on the prevalence of constipation difficulties reflect the complexities of the management of this; evidence from Implementation studies and Constipation / continence services of having lead professionals who can advise colleagues on individual cases / cascade seems not to be reflected in these Standards.

ID	Stakeholder	Statement no	Comments
			6. Use of the word 'blockage' seems inappropriate - this wording and faecal impaction again support the impression that that this is aimed at inexperienced professionals ref 3b response.
35	Royal Pharmaceutical Society	Statement 3	As experts in medicines, pharmacists offer advice on how to take medicines, adverse effects, possible interactions and cautions and offer advice to patients and their carers when they are experiencing difficulties in taking their medicines, encouraging medicines adherence. Community pharmacies are conveniently located with long opening hours, making them readily accessible with no need to make an appointment, particularly for patients who are experiencing difficulties.
36	British Society of Paediatric Gastroenterology & Nutrition	Question 3	It could vary but may be sufficient to review once, but often requires regular contact with health professi0onals and this should be stated. Specifically, 1. Follow up should be arranged soon after initial disimpaction treatment (in clinic or by phone) within a week with a view to starting maintenance treatment. This longer term needs to be prescribed at that point if not already prescribed at the initial appointment. 2. If follow up is not given until 6 weeks later (and maintenance treatment has not been already prescribed), then the initial disimpaction treatment could be futile as the problem may have recurred if the next advice is given 6 weeks later.
37	Central Manchester Foundation Trust	Question 3	Clinics enable regular follow up dependent on need. Initial consultation at home followed by either week follow up for children on disimpaction and regular follow-up, every 4-6 weeks for those on maintenance
38	Leeds Teaching Hospitals NHS Trust	Question 3	I think the review within 1 week for disimpaction treatment is likely to be carried out less well, and so needs more emphasis.
39	Rotherham Doncaster and South Humber NHS Foundation Trust	Question 3	Both need improvement and to be able to evidence this in relation to transfer of care form secondary care to primary care
40	Royal College of Surgeons Edinburgh	Question 3	RCSEd suspects that both early review in impacted cases and later review in maintenance therapy are equally neglected.
41	British Society of Paediatric Gastroenterology & Nutrition	Statement 4	**This QS statement** may deter colleagues in primary care from dealing with the problem as they may not have the time to so this. It may not be necessary if sensible literature is available for families that are parent held and can be shared with the GP, HV and family. Colleagues in secondary and tertiary care may not have time to write this out in clinic and it will not be as comprehensive as the excellent literature that is available.

ID	Stakeholder	Statement no	Comments
42	NHS Direct	Statement 4	This statement supports the importance of clear information about the condition as appropriate. I think it is important to provide a template written fact sheet.
43	Royal College of Paediatrics and Child Health	Statement 4	We recommend that NICE GLs on having a professional point of contact are emphasised plus that any plan reflects the NICE G details. 1. What ifs: Not to reduce doses without clear and understandable reasons /in well-established maintenance phase / or with early or weekly contact. 2. Access to a point of professional advice by telephone to leave messages and queries over initial management phase.
44	Royal Pharmaceutical Society	Statement 4	Pharmacists provide detailed written (as well as verbal) information on medicines and have an important role in ensuring that patients and their carers receive clear written instructions on how to take their medicines.
45	Welsh Government	Statement 4	Regarding “a written personalised management plan” will again put off colleagues in primary care from dealing with the problem. They simply never have the time to do this. Neither is it necessary. Further, colleagues in secondary and tertiary care do not have the luxury of sufficient time to draft “a written personalised management plan” for every child with constipation. What would be better would be to direct parents to the appropriate area of the NICE website where appropriate generic advice should be available and applicable.
46	British Society of Paediatric Gastroenterology & Nutrition	Question 4	It may be better to better to suggest that pre prepared generic information that can be easily personalised regarding drug doses and regimes should be provided. How and when to contact the local provider is also important. It should also direct parents to the appropriate area of the NICE website where appropriate generic advice should be available and applicable.
47	Central Manchester Foundation Trust	Question 4	I feel the most important piece of information to be input is as follows: Information about how bowels work, symptoms that might indicate a serious underlying problem, how to take their medication, what to expect when taking laxatives, how to poo, origins of constipation, criteria to recognise risk situations for relapse and the importance of continuing treatment until advised otherwise by the healthcare professional
48	Leeds Teaching Hospitals NHS Trust	Question 4	The most important piece of information that should be provided as part of a written personalised management plan is practical information about using Movicol: adjustable; things might get worse initially; don’t stop too soon (even if seem improved).
49	Rotherham Doncaster and South Humber NHS Foundation Trust	Question 4	Personalised care plan – needs to be clear and client focussed – what treatment is and dose adjustments very important and how they decide to make these adjustments, also clear when to seek review

ID	Stakeholder	Statement no	Comments
50	Royal College of Nursing	Question 4	An explanation of the diagnosis process, information about lifestyle advice, medication and review dates would be helpful information for the child and family to have.
51	Royal College of Paediatrics and Child Health	Question 4	The management plan should include advice on how to avoid a recurrence in the future.
52	Royal College of Surgeons Edinburgh	Question 4	The College suggests that the most important piece of information that should be provided, as part of a written personalised management plan, is considering advice on how to adjust laxative dosage in light of response to the most important information, especially in case of impaction.
53	British Society of Paediatric Gastroenterology & Nutrition	Statement 5	The children need to be reviewed by their GP first (standards say that initial assessment could be done by school nurse or health visitor and it is important that they need to consult GP before referring on) and then only be referred to a general paediatrician. One of the commonest reasons that children remain constipated is that they have not taken their medication and the protocol would need to be clear that before referral, the health professional would need to determine if the treatment plan had been adhered to. We suggest changing the word from specialist to a “Paediatrician”. Otherwise tertiary gastroenterology service would be swamped by inappropriate constipation referrals.
54	Paediatric Continence Forum	Statement 5	PCF recommends that upon referral, children and young people 0-19 years with idiopathic constipation should be treated by professionals within the context of community based paediatric services that also treat other conditions such as daytime incontinence and nocturnal enuresis, plus advice on toilet training. The service should include working with children and young people with learning difficulties and physical disabilities.
55	Royal College of Paediatrics and Child Health	Statement 5	We would like to ask who are the ‘specialists’ and what is their role? How many Community Paeds take on non neuro devel / non CP work? What should ‘specialists‘ be commissioned to do? A lead continence nurse as suggested above to guide and advise other professionals (mainly) would be a better use of resources than patchy knowledge across an area How should ‘specialists’ then work with their primary care colleagues to optimise management; who is checking and offering the proactive advice that is needed.

ID	Stakeholder	Statement no	Comments
56	Royal College of Paediatrics and Child Health	Statement 5	When referring to a specialist, it is important that primary care health professionals remain involved in the care of the child's constipation. Sometimes, once a child or young person has been referred to specialist services, universal primary care services may partly or fully withdraw to the detriment of that child's or young person's care.
57	British Society of Paediatric Gastroenterology & Nutrition	Question 5	It isn't clear what "response to initial treatment "means. We suggest that this is stated very clearly in the QS.
58	Central Manchester Foundation Trust	Question 5	I feel as long as there are sufficient local arrangements, written clinical protocols and appropriate information for child /family sufficient to statement of referring to specialist care if the child does not respond to treatment within 3 months should be fine.
59	Leeds Teaching Hospitals NHS Trust	Question 5	I think it is generally clear what 'respond to initial treatment' means , but could be clarified further for audit purposes (eg not responding means there has been no significant progress as judged by either the health professional or the parents (and child).
60	Rotherham Doncaster and South Humber NHS Foundation Trust	Question 5	Yes
61	Royal College of Nursing	Question 5	It would be helpful to use the Bristol Stool form scale. Could use number of type 4 stools per week.
62	Royal College of Paediatrics and Child Health	Question 5	This is unclear and needs more detail, cross reference and clarification: initial response to initial treatment may be ……..; is just the start of management which often needs dose adjustment.
63	Royal College of Surgeons Edinburgh	Question 5	RCSEd believes that it is not clear what 'respond to initial treatment' means. The College would suggest that the quality standard should clarify that this means improvement in symptoms but not necessarily weaning and discontinuation of laxative treatment. Symptom free treatment over the time frame specified is considered successful treatment.