NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Gastro-oesophageal reflux in children and young people

Date of Quality Standards Advisory Committee post-consultation meeting:
21 October 2015

2 Introduction

The draft quality standard for gastro-oesophageal reflux in children and young people was made available on the NICE website for a 4-week public consultation period between 21 August and 21 September 2015. 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 12 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 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 appendix 1.

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?

3. For each quality statement what do you think could be done to support improvement and help overcome barriers?

4 General comments

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

- Stakeholders were supportive of the quality standard.
- Stakeholders felt that the quality standard reflected appropriate areas for quality improvement.
- Stakeholders highlighted that complex needs of children and young people with neuro disabilities were not reflected within the quality standard.

Consultation comments on data collection

- Stakeholders felt that provided the required systems and structures were available, data collection would be possible for the proposed quality measures.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

People attending antenatal and postnatal appointments are given information about gastro-oesophageal reflux (GOR) in infants.

Consultation comments

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

- adding information about GOR to antenatal classes would unnecessarily add to the volume of information future parents need to take in;
- adding information about GOR to antenatal classes can potentially increase anxiety and result in over diagnosis followed by parents changing to formula milk without consulting with a healthcare practitioner;
- information about reflux should be reserved for postnatal discussions about infant feeding where it is relevant to the babies' symptoms;

5.2 Draft statement 2

Infants with frequent regurgitation associated with marked distress have their feeding assessed.

Consultation comments

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

- the statement should specify that the assessment should be carried out by a specialist skilled in infant feeding support

- infants with frequent regurgitation associated with marked distress should also be assessed for non-IgE mediated cow's milk allergy particularly if they have one or more signs and symptoms of food allergy

5.3 Draft statement 3

Infants with frequent regurgitation associated with marked distress that continues despite a feeding assessment and advice have a trial of alginate therapy.

Consultation comments

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

- statement 3 implies that alginates are the first line intervention after a feeding assessment without acknowledging earlier elements of the stepped care approach recommended within the NICE guideline NG1
- trial of alginate therapy for 1-2 weeks may not be enough - may need to extend to 3-4 weeks
- dosage should be defined as a lot of primary care practitioners are reluctant to prescribe adequate dosage

5.4 Draft statement 4

Infants and children with no visible regurgitation and only 1 symptom associated with gastro-oesophageal reflux (GOR) are not further investigated or treated for GOR.

Consultation comments

No comments made specifically on this statement.

5.5 Draft statement 5

Infants, children and young people with vomiting or regurgitation and any 'red flag' symptoms are further investigated or referred to specialist care.

Consultation comments

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

- changes to referral pathways included in the Red flag table

5.6 Draft statement 6

Infants, children and young people do not have an upper gastrointestinal (GI) contrast study to diagnose or assess the severity of gastro-oesophageal reflux disease (GORD).

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- children and young people with complex neurological and neuromuscular conditions may need contrast study and advising that it is not needed may be incorrect

5.7 Draft statement 7

Infants and children with visible regurgitation as an isolated symptom are not prescribed acid‑suppressing drugs.

Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

- there is often considerable pressure on GPs from parents to prescribe acid‑suppressing drugs after failure of alginate treatment and difficultly getting a specialist care opinion

5.8 Draft statement 8

Infants, children and young people are not prescribed domperidone, metoclopramide or erythromycin to treat gastro-oesophageal reflux (GOR) or gastro-oesophageal reflux disease (GORD) without specialist paediatric advice.

Consultation comments

Stakeholders made the following comments in relation to draft statement 8:

- Additional information about Metoclopromide and Domperidone

6 Suggestions for additional statements

- No additional areas suggested

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement No	Comments
1	Royal College of Pathologists	General	I am just writing to inform you that the Royal College of Pathologists has no comments to make on this consultation.
2	NHS England	General	I wish to confirm that NHS England has no substantive comments to make regarding this consultation
3	Department of Health	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
4	British Society of Gastroenterology	General	The Quality Standards are well written and reflect important areas for quality improvements in GOR in children and young people. Provided the required systems and structures were available, it would then be possible to collect data for the proposed quality measures.
5	The Royal College of General Practitioners	General	These quality standards seem relevant. Thank you!
6	Alder Hey Children's NHS Foundation Trust	General	The NICE emphasis is almost entirely on primary and secondary care and says almost nothing about the tertiary care of complex cases, particularly the very large subgroup of children with neuro-disability. Alder Hey wishes to stress the size and complexity of this group of patients and the range of surgical options that are available and being used across the UK and elsewhere. It is worth mentioning that oesophago-gastric dissociation is offered in at least 8 major centres, FVP in at least 3, and jejunostomy in at least 18.
7	The Royal College of General Practitioners	Quality Statement 1	I was surprised at the reminder to mention it at the 6-8 week check but no reflection, many mothers have asked me about it recently and several have asked for an alginate.
8	Royal College of Paediatrics and Child Health	Quality statement 1	Page 8 faltering growth needs more specification for e.g. drop in centiles over what period to make it explicit to the health professionals. Also on the same page frequency needs to be defined as what would be accepted as normal.

9	NCT	Quality statement 1	There is a danger that adding information about potential infant reflux to antenatal appointments will result in overload of information. Parents already complain that there is too much to take in. Information about a relatively unusual condition, about which nothing can be done before the baby is born, may either increase anxiety, reduce confidence in parenting and/or increase the chance of over-diagnosis and parental diagnosis of reflux in newborn babies. Some parents will change to a formula milk advertised as suitable for babies with reflux without speaking to a health professional and potentially stop breastfeeding in order to do so. NCT suggests information about reflux is reserved for postnatal discussions about infant feeding where it is relevant to the babies' symptoms.
10	NCT	Quality statement 2	ADD … by a specialist skilled in infant feeding support
11	Food Allergy Specialist Group of the British Dietetic Association	Quality statement 2	Recommend that infants with frequent regurgitation associated with marked distress should also be assessed for non-IgE mediated cow's milk allergy particularly if they have one or more signs and symptoms of food allergy as detailed here: http://pathways.nice.org.uk/pathways/food-allergy-in-children-and-young-people#content=view-node%3Anodes-initial-recognitionA trial of an extensively hydrolysed infant formula milk, amino acid formula milk or a cow's milk elimination diet in the case of breastfeeding infants followed by reintroduction would help confirm such a diagnosis. Waiting for a feeding assessment followed by a trial of alginates and only in presence of 'red flag' symptoms prior to considering allergy risks delayed diagnosis and potential for development of or exacerbation of feeding problems.
12	Royal College of Paediatrics and Child Health	Quality statement 2	Page 10 Feeding assessment is useful but what are normal requirements for an infant /child should be clarified as this will allay parents anxiety. Page 12 marked distress could vary depending on perception of the carer/parent and again although difficult to define but addressing he above will prove to be beneficial.
13	Royal College of Paediatrics and Child Health	Quality statement 3	Page 15Trial of alginate therapy for 1-2 weeks may not be enough may need to extend to 3-4 weeks sometimes and also dosage needs to be defined as reference as a lot of primary care colleagues are very reluctant and may not prescribe adequate dosage.

14	Sheffield Children's Hospital	Quality statement 3	This QS implies that alginates are the first line intervention after a feeding assessment. This is in conflict with NG1 which states: In formula-fed infants with frequent regurgitation associated with marked distress, use the following stepped-care approach: - review the feeding history, then - reduce the feed volumes only if excessive for the infant's weight, then - offer a trial of smaller, more frequent feeds (while maintaining an appropriate total daily amount of milk) unless the feeds are already small and frequent, then - offer a trial of thickened formula (for example, containing rice starch, cornstarch, locust bean gum or carob bean gum).
15	Cheshire and Wirral Partnership Trust	Quality statement 3	Regarding statement 3 I am very disapointed that a trial of thickened formula has not been included if not breast feeding as that was the first line- feeding assessment followed by trial of thickened formula before going onto gaviscon
16	Royal College of Paediatrics and Child Health	Quality Statement 3	There is no mention of children with neurological and muscular problems as they have higher incidence of reflux and although they are under care of community Paediatrician will encounter primary care colleagues and they will need investigation and treatment .They could be misdiagnosed with epilepsy as sandifers syndrome and an awareness is essential so they don't.
17	British Society of Paediatric Radiology (BSPR) / The Royal College of Radiologists (RCR)	Quality statement 5	Page 20 - Frequent forceful (projectile) vomiting – Paediatric Surgical referral: The BSPR and RCR suggest that when direct access is unavailable referral to the on call paediatric team to consider getting an urgent ultrasound to look for hypertrophic pyloric stenosis.
18	British Society of Paediatric Radiology (BSPR) / The Royal College of Radiologists (RCR)	Quality statement 5	Page 20 - Bile stained vomiting - Paediatric Surgical referral: The BSPR and RCR suggest that when direct access is unavailable referral to the on call paediatric team to consider getting an urgent upper GI contrast study to look for malrotation.
19	Food Allergy Specialist Group of the British Dietetic Association	Quality statement 5	In 'red flag' symptoms consider that frequent projectile vomiting may be indicative of non IgE-mediated allergy.

20	Royal College of Paediatrics and Child Health	Quality statement 6	Page 23 selective populations (complex neurological and Neuromuscular conditions) will need contrast study for GO reflux and hence advising that it is not needed may be incorrect!
21	The Royal College of General Practitioners	Quality Statement 7	Infants and children with visible regurgitation as an isolated symptom are not prescribed acid suppressing drugs. There is often considerable pressure on GPs from parents to prescribe these after failure of alginate treatment and difficultly getting a specialist care opinion.
22	Royal College of Paediatrics and Child Health	Quality statement 8	Metoclopromide will be needed for enhancing gastric motility in a lot of end of life care with caution and Domperidone is much less widely used due to effects of cardiac rhythm .There is no mention of the above in the statement.

Registered stakeholders who submitted comments at consultation

- Alder Hey Children's NHS Foundation Trust
- British Society of Gastroenterology
- British Society of Paediatric Radiology (BSPR) / The Royal College of Radiologists (RCR)
- Cheshire and Wirral Partnership Trust
- Department of Health
- Food Allergy Specialist Group of the British Dietetic Association
- National Childbirth Trust (NCT)
- NHS England
- Royal College of General Practitioners
- Royal College of Paediatrics and Child Health

- Royal College of Pathologists
- Sheffield Children’s Hospital