NATIONAL INSTITUTE FOR HEALTH AND   
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Faltering growth

Date of quality standards advisory committee post-consultation meeting:   
10 March 2020

1. Introduction

The draft quality standard for faltering growth was made available on the NICE website for a 4-week public consultation period between 24 January and 21 February 2020. 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 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.

1. 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. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

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

4. For draft quality statement 1: Will this quality statement help to improve identification of faltering growth in babies?

1. General comments

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

* General agreement that the quality standard reflects key areas for quality improvement.
* Suggestion to include coeliac disease in the list of quality standards that should be considered when commissioning or providing faltering growth services.

### Consultation comments on data collection

* One stakeholder felt local systems and structures are in place to collect the data for the measures in the quality standard, another felt there is limited resource to collect the data.

### Consultation comments on resource impact

* One stakeholder felt that the statements are achievable. Another felt that they would not be achievable in all parts of the UK due to limited funding and resources to support training.
* One stakeholder had concerns about the decreasing number of health visitors and noted that due to decreases funding some areas will no longer be undertaking the five mandated checks.

1. Summary of consultation feedback by draft statement
   1. Draft statement 1

Babies have their weight plotted on a growth chart at planned intervals.

### Consultation comments

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

* This moves responsibility for weighing under 5s from health visitors to general practice.
* Change to healthcare professional weighing ‘around the time’ of the vaccinations.
* This statement should be reworded to avoid confusion with population screening.
* Length/height and head circumference need to be measured at defined intervals.
* Healthcare professionals need to be trained to collect, plot and interpret measurements.
* Paediatric dietetic teams should be involved in training.
* Access to growth charts is essential but not always possible.
* Data is not always acted upon if collected.
* ‘Planned intervals’ should be explained in the statement wording.

Measures

* Structure measure a)
  + There is reduced access to weight measurement and time available within health visitor clinics to plot the information.
  + Suggestion to encourage parents to take responsibility for plotting the weight and understanding when to seek help from a health care professional.
* Process measure a)
  + As the growth chart is in the personal health record held by parents / carers it is not clear how this data could be collected.
* Process measure b)
  + It is not clear who will weigh at 1 week.
  + Reword to ‘recorded’ instead of ‘plotted’ as the growth charts do not allow for measurements to be plotted between birth – 2 weeks of age.
* Process measure c)
  + Most GP surgeries do not have appropriate scales to weigh babies.
* Measures are not currently in place for this statement and there is a cost associated with training staff.
* Additional costs would be balanced out because faltering growth would be diagnosed sooner meaning correct management could be put in place.

Audience descriptors

* Include equipment being available to measure babies.
* Explain what is meant by ‘appropriate intervals’ for healthcare professionals.
* Concerns over faltering growth cannot be raised unless an initial length/height has been plotted.

Definition of planned intervals

* Unclear why timing of weighing is aligned to the vaccination schedule.
* Midwifery services weigh at days 5 and 10. Weighing at 1 week is a change in practice.

### Consultation question 4: Will this quality statement help to improve identification of faltering growth in babies?

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

* Two stakeholders felt this statement would help to improve identification of faltering growth in babies and one felt it would not.
* Suggestion to specify and elaborate on investigations.
* Suggestion that parents who do not take their child for immunisations are told to ensure their baby is weighed and measured at these intervals.
  1. Draft statement 2

Babies and preschool children have a detailed feeding or eating history taken if there are concerns about faltering growth.

### Consultation comments

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

* Remove information about calorific value of diet from the rationale as a full dietary assessment would not be done at the identification stage.
* Suggestion to replace calorific value with energy and protein content.
* Referral to paediatric dietitians as part of a management plan is needed as health visiting teams do not have adequate skill, access to training or resource to do this.

Audience descriptors

* A stakeholder was pleased to see the importance of adequate time for assessment emphasised.

Definitions

* Definition of feeding or eating history
  + Needs more detail, is not from the NICE guidance and should highlight where more information can be obtained.
  + Replace severity of weight loss with severity of weight faltering.
  + Add assessment of whether a baby is effectively transferring milk from the breast and drinking to the definition and training for professionals.
* Definition of concerns about faltering growth - weight should return to birth weight by 2 weeks not 3.
  1. Draft statement 3

Babies and preschool children have a management plan with specific goals if there are concerns about faltering growth.

### Consultation comments

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

* Suggestion to add ‘when medical causes have been excluded’ to the statement.
* Local pathways for the management of infants and children identified with faltering growth are needed.
* Suggestion to include a specific reference to serological testing for coeliac disease.

Measures

* There was support for the structure measures.
* Structure measure b)
  + Resource limitations in health visiting services mean GPs and health visitors do not meet regularly. Many health visiting services directly refer to secondary care.

Definitions

* Definition of primary care team - include children’s nurses and school nurses.
* Definition of healthcare professionals with expertise in faltering growth - change baby feeding specialist to infant feeding specialist and add lactation consultants.
  1. Draft statement 4

Mothers are supported to continue breastfeeding if their baby is given supplementation with formula because of concerns about faltering growth.

### Consultation comments

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

* Emphasise in the rationale that the priority is supporting the mother to continue to breastfeed as this is not clear.
* Add to the rationale that this can also help with breastfeeding being continued in the second 6 months and beyond.
* Include mothers receiving information on how to increase their own milk supply so they can resume exclusive breastfeeding after supplementation.
* Parents need more access to education around persisting with breastfeeding.
* Health visiting teams are not always adequately trained to support breastfeeding.
* Include infant feeding advisors and breastfeeding support professionals.
* Include information about supplementation with human milk.

Audience descriptors

* Expressing milk will not resolve low milk supply caused by poor milk transfer, an attachment and milk transfer assessment by a lactation consultant is needed.

1. Suggestions for additional statements

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

* Assessment of tongue-tie.
* Re-establishment of mothers’ milk banks in all communities.
* Other causes for faltering growth, including infections and medical conditions, should be included.

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| ID | Organisation name | Statement No | Comments |
| --- | --- | --- | --- |
| **General** | | | | |
| 1 | Coeliac UK | Other quality standards that should be considered | The draft quality standard signposts to a number of other quality standards which should be considered when commissioning or providing faltering growth services. The quality standard on coeliac disease (QS134) is not included within this list. We feel that the quality standard should be included because of the relevant recommendation (Quality statement 1) that a serological test should be offed to children with faltering growth. |
| 2 | Royal College of Paediatrics and Child Health | General | The reviewer noted that from a nephrology perspective, the quality standard is good. |
| 3 | Royal College of Physicians |  | The RCP is grateful for the opportunity to respond to the above consultation.  We would like to endorse the response submitted by the RCPCH. |
| **Question 1** | | | | |
| 4 | British Dietetic Association | Question 1 | Yes |
| 5 | Royal College of Paediatrics and Child Health | Question 1 | The reviewer agrees that this draft quality standard accurately reflects the key areas for quality improvement. |
| **Question 2** | | | | |
| 6 | British Dietetic Association | Question 2 | No. There is limited input by many community health surveillance teams (also known as health visiting) across the UK due to a large reduction and disparity in funding to services in certain areas. Where teams exist, there is limited resource to collect this data but where collected, it is not acted upon in a timely or appropriate manner. |
| 7 | Royal College of Paediatrics and Child Health | Question 2 | The reviewer believes that local systems and structures are in place to collect data for the proposed quality measures. |
| **Question 3** | | | | |
| 8 | British Dietetic Association | Question 3 | Not in all areas in the UK, and there will be limited access to funding and resource to support appropriate training. |
| 9 | Royal College of Paediatrics and Child Health | Question 3 | The reviewer believes that the statements in this standard are achievable. |
| 10 | Royal College of Nursing | Question 3 | We welcome the standards but express concern about the decreasing number of health visitors and due to decreases in public health funding and local authority funding, that some areas have stated that they will no longer be undertaking the five mandated checks as indicated in the standards. |
| **Question 5** | | | | |
| 11 | Royal College of Paediatrics and Child Health | Question 5 | The reviewer explained how a 3-month-old baby was referred with faltering growth. A heart murmur was heard but examination was otherwise unremarkable. The infant was referred for routine cardiac assessment. A consultant with an interest in cardiology had difficulty performing ECHO because of the screaming child; the examination was still unremarkable (no cyanosis) but oxygen saturation was not performed on both appointments. He was referred to the cardiology unit non-urgently. The child was seen at six months of age and found to have very rare congenital heart disease (TA type IV). The child survived, however, ten years later the adoptive mother sued the Trust for apparently delaying the diagnosis, although this has been denied. CHD without clinical signs is a rare cause of faltering growth. |
| **Statement 1** | | | | |
| 12 | British Dietetic Association | Statement 1 | Length and head circumference are not checked which is imperative to the interpretation of growth. Appropriate training must also be accessible to those collecting these measures of growth. Access to growth charts is vital, and not always possible. Training on plotting and interpretation of growth on growth charts is also essential. |
| 13 | British Dietetic Association | Statement 1 | Often measurements of length and head circumference are not checked, nor understood in the context of normal growth, alongside measures of weight. This demonstrates the lack of understanding, skill and training. Paediatric dietetic involvement is therefore essential to help execute training in this sector, to better manage the collection of these measure, to ensure breastfeeding is supported, and to identify when referral to specialist management is required. If this is not appropriately managed, parental anxiety may increase which negatively impacts on the infant. |
| 14 | Child Growth Foundation | Statement 1 | It is imperative that not only weight is measured but also length/height at defined intervals.  We would recommend the following:  Birth - weight and length  10-14 days - weight  6-8 weeks - weight  12 weeks - weight and length  16 weeks - weight  6-8 months - weight and length  12 months - weight and length  Annually for both weight and height throughout primary years  Height/length must be considered alongside weight measurements, as this is important to monitor faltering growth and any underlying growth problems.  Weight alone is not an accurate indicator of faltering growth. |
| 15 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 1 – process b | The UK WHO growth charts do not allow for measurements to be plotted between birth – 2 weeks of age. The sentence in this standard reads as though professionals should plot a babies weight at 1 week of age. I suggest that the words ‘plotted on’ are replaced with ‘recorded in’ to avoid confusion about plotting growth at 1 week of age when there are no centile lines on the chart. |
| 16 | Child Growth Foundation | Statement 1 - question 2 | Measures are not currently in place. It is feasible, but there is a cost associated with this. HCP’s must be trained in accurate measurements and more expertise and knowledge to refer to the relevant health teams. |
| 17 | Child Growth Foundation | Statement 1 - question 3 | Costs would be evened out because faltering growth would be diagnosed sooner, therefore correct management can be put in place. |
| 18 | First Steps Nutrition Trust | Statement 1 | On page 5, data source b – it is not clear who is doing the one week check, and therefore who is undertaking the weighing and recording of the measurement. This needs to be clarified.  On page 7, ‘planned intervals’, it is not clear where the proposal to align routine weighing of babies with the vaccination schedule has come from and on what basis this proposal is made. This should be provided. As an alternative, consideration should be given to seeking that universal, mandated health visitor checks should include routine growth monitoring for the following reasons: 1. In England and Scotland there is a check at 3-5 weeks, in Northern Ireland there is one at 6 weeks and in Wales the first check after the 10-14 days visit is at 6-8 weeks. A weight check before the suggested check at the time of the 8 week vaccinations would help identify early growth faltering and lead to the earlier provision of support and advice to the parents/carers of these children. 2. Health visitors should already have the training and skills to perform accurate weight measurements. 3. Health visitors should already have the training and skills to provide appropriate advice on next steps including making appropriate referrals for care for those children found to have faltering growth |
| 19 | Oxford Health NHS Foundation Trust | Statement 1 p.7 | Babies are weighed at 1 week? Midwifery Services weigh babies at Day 5 and then Day 10 routinely rather than at 1 week – would this mean a change in practice. This would be difficult to change within midwifery practice as babies are weighed at Blood Spot visit at 5 days and then discharge at 10 days |
| 20 | Royal College of General Practitioners | General | This document is well received and it is essential not to miss faltering growth in children. However, it is important to note that weight measurement in those under 5 has routinely been performed by health visitors and not GP surgeries. This document shifts the emphasis significantly towards the GP surgery being responsible for this and before its publication we would welcome a financial and resource impact consideration to these recommendations. In its current format it is unlikely that the RCGP could endorse this quality standard.  Can the committee consider rewriting the document to include a health care professional taking a weight “around the time” of the 8, 12 and 16 week vaccination rather than “AT” the time of the immunisation which would put the emphasis onto primary care nurses and away from health visitors. |
| 21 | Royal College of General Practitioners | Statement 1 - structure a | Whilst weights are often written down in numerical form, it is common for these not to be plotted by health care professionals. Funding for health visitors has significantly reduced and this is causing reduced access to weight measurement and time available within their clinics to plot the information on a graph. Could the quality standard encourage the parents to take responsibility for plotting the weight and understanding when to seek help from a health care professional? |
| 22 | Royal College of General Practitioners | Statement 1 - structure c | Immunisations are carried out by primary care nurses within a GP surgery in almost all cases. Most GP surgeries do not have appropriate scales to weigh babies. The routine review of weight traditionally falls under the remit of the health visitor within a clinical environment that is usually not associated with the GP surgery, or at the time of immunisations. Many new parents are feeding back that health visitor services and clinics are being cut and access to these clinics for routine weights is diminishing.  If this service is to be transferred to GP surgeries, appropriate funding for equipment will need to be in place to perform this and nurses trained in their use which will have implications in time and funding. |
| 23 | Royal College of General Practitioners | Statement 1 - process a | Children’s weights are plotted in personal health records that are the property of the parents and not left with the health care professions. To audit the number of weights plotted onto a growth chart would be very difficult, if not impossible, with patient held notes and so this quality standard is unlikely to be undertaken in a primary care environment. It is not clear how this data would be collected and measured. |
| 24 | Royal College of Nursing | Statement 1 – audience descriptors | Page 6: “*If there are concerns about faltering growth, arrangements are made for babies to be weighed and their length measured again at appropriate intervals*...”  Concerns over faltering growth cannot be raised unless a baby or child has had an initial length/height plotted |
| 25 | Royal College of Nursing | Statement 1 – audience descriptors | Page 6: Service providers: “*Service providers such as maternity services, GP practices and health visiting services) ensure that calibrated equipment is available for babies to be weighed, and that staff are trained to weigh and measure them.* “  Where can healthcare professionals gain necessary skills to measure and record height and weights? British Medical Journal (BMJ) module for faltering growth below is useful  <https://learning.bmj.com/learning/module-intro/faltering-growth.html?moduleId=10063880&locale=en_GB> |
| 26 | Royal College of Paediatrics and Child Health | Statement 1 | ‘Planned intervals’ is too vague. While the detail is developed in the explanatory section, the headline quality statement is not clear about what planned intervals means or how it might vary between children. |
| 27 | Royal College of Paediatrics and Child Health | Statement 1 – audience descriptors – service providers | Guidance to service providers should probably say ‘…calibrated equipment is available for babies to be weighed and measured, and that staff are trained to weigh and measure them’. |
| 28 | Royal College of Paediatrics and Child Health | Statement 1 – audience descriptors – healthcare professionals | The statement could be much clearer about what is meant by appropriate in “…babies are weighed, and their length is measured at appropriate intervals” |
| 29 | UK National Screening Committee | Statement 1 - measures | The UK NSC defines population screening when a test is offered to *all* members of a (usually demographically) defined population who do not necessarily perceive that they are at risk of, or are already affected by, a disease or its complications.  Therefore, statement 1 as is currently phrased it seems to imply that there is the intention to weigh and measure all babies, this is in effect screening for faltering growth in babies and children. However, your NG75 (recommendations section 1.2) refers to children a slow rate of weight gain than expected for age and sex, so for these children there is a concern of faltering growth. The UK NSC therefore suggests that this should be captured in Statement 1 to avoid confusion with population screening. |
| 30 | University Hospitals Birmingham | Statement 1 | Comment that alongside this guidance weight should be measured at every contact with a health care professional in infancy and preschool years. |
| **Question 4** | | | | |
| 31 | British Dietetic Association | Question 4 | No. |
| 32 | Cheshire & Wirral Partnership NHS Foundation Trust | Question 4 | Yes this statement will help to improve the identification of faltering growth in babies. Would it be sensible to mention for parents who do not take their child for immunisations that they ensure their baby is weighed and measured at these intervals? |
| 33 | Oxford Health NHS Foundation Trust | Question 4 | This quality statement will help to improve identification of faltering growth in babies |
| 34 | Royal College of Paediatrics and Child Health | Question 4 | The reviewer noted that it would be helpful to elaborate on and specify investigations. |
| **Statement 2** | | | | |
| 35 | British Dietetic Association | Statement 2 | Health visiting teams currently do not have adequate skill, access to training or resource to collect this measure. Collection of detailed diet history requires trained personnel who are able to obtain a comprehensive understanding of normal eating habits and interpret the information collected. Referral to paediatric dietitians will enable the collection of this measure appropriately, as part of a management plan. |
| 36 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 2 | For breastfed babies the feeding history should also include: The number of breastfeeds in 24 hours, whether 1 or 2 breasts are offered, and whether or not the baby is actively drinking whilst at the breast (sucking and swallowing).  I suggest that there is emphasis on professionals being adequately trained to be able to assess whether or not a baby is ‘drinking’ at the breast. In clinical practice a baby is often seen at the breast and assumed to be breastfeeding when actually they are not effectively transferring milk from the breast and drinking.  In preschool children and babies over 6 months I suggest we include a further bullet point stating:  If the child attends a childcare setting, check all of the above with childcare staff and explore any inconsistencies between home setting and childcare setting |
| 37 | First Steps Nutrition Trust | Statement 2 | We broadly agree with the statement, but the sentence in the rationale on page 8 that the assessment can ‘provide information about the calorific value of their diet’ should be taken out as a proper dietary assessment would not be done at this identification stage. Dietary assessment is not a simple task for someone who has not trained in dietetics/ is a registered public health nutritionist and could lead to the collection of highly misleading information.  The definitions used in this quality statement are also inadequate and need more detail (specifically on page 10 the section ‘Feeding or eating history’). Whilst it is understood that the text on page 10 is not intended to be comprehensive (as indicated by the phrase ‘can include’), this detail is not provided in NICE’s full guidance on faltering growth and there are no references in this guidance on where to get more information. |
| 38 | Royal College of Paediatrics and Child Health | Statement 2 - rationale | ‘Calorific value’ would be better described as energy (and possibly protein) content. |
| 39 | Royal College of Paediatrics and Child Health | Statement 2 – audience descriptors - service providers | It is great to see the importance of adequate time for assessment emphasised. |
| 40 | Royal College of Paediatrics and Child Health | Statement 2 | The paragraph “The detailed feeding or eating history is tailored to the individual infant or child taking into account a broad range of other factors, e.g. age, severity of weight loss, but also other factors…” should say the severity of weight faltering, since faltering does not often result in weight loss. NG75 recommends referral to secondary care for persistent weight loss as this is unusual. |
| 41 | University Hospitals Birmingham | Statement 2 | Concerns about faltering growth, normally weight should return to birth weight by 2 weeks not 3. |
| **Statement 3** | | | | |
| 42 | British Dietetic Association | Statement 3 | There is a need to develop local pathways for the management of infants and children identified with faltering growth. This requires paediatric dietetic involvement to design and implement within services across the UK. Local services must review their systems to understand how they can evolve to support these quality measures. GP appointments could be avoided if a clear pathway was implemented with timely access to a local paediatric dietetic service. |
| 43 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 3 – definition of management plan | I suggest the final bullet point should include in brackets (this should include a lactation consultant for breastfed babies). Rational: In clinical practice I do not feel this is an obvious referral to most professionals and makes such a difference to breastfed babies who are faltering to grow and despite the outcome leads to a large percentage of families feeling supported.  I suggest under Healthcare professionals with expertise in faltering growth the first bullet point ‘baby feeding specialist’ includes in brackets (these include lactation consultants). Rationale: to raise the profile of the importance of lactation consultants as I feel this is still not an obvious choice for professionals |
| 44 | Coeliac UK | Statement 3 | Quality statement 3 refers to a management plan for babies and preschool children if there are concerns about faltering growth. We are reassured to see that this includes reference to assessments or investigations but feel this is a missed opportunity to not include a specific reference to serological testing for coeliac disease.  1 in 100 people have coeliac disease but only 30% are currently diagnosed.[1] Children with coeliac disease may present with faltering growth and NICE NG20 recommends that children with coeliac disease should be offered a serological test for coeliac disease.[2]  An early diagnosis of coeliac disease is important to improve symptoms and to reduce the risk of the long term complications of coeliac disease. Undiagnosed coeliac disease can result in long term complications including malnutrition, osteoporosis, intestinal malignancy, ulcerative jejunitis and functional hyposplenism.[2]  [1] West J, Otete H, Sultan AA, Crooks CJ. Changes in Testing for and Incidence of Celiac Disease in the United Kingdom. Epidemiology [Internet]. 2019 Jul;30(4):e23–4. Available from: <http://dx.doi.org/10.1097/EDE.0000000000001006>  [2] NICE, NG20 Coeliac disease; recognition, assessment and management. 2015. |
| 45 | First Steps Nutrition Trust | Statement 3 | We agree with this statement, but in line with 1.3.3 in NG 75, the label ‘baby feeding specialists’ on page 15, under the list of health care professionals with expertise in faltering growth, should be replaced with ‘infant feeding specialist’, which usually includes specialist lead midwives and health visitors who have received additional training. |
| 46 | Lactation Consultants of Great Britain | Statement 3 | Lactation Consultants of Great Britain welcome the inclusion of Quality measures within Quality Statement 3, and local pathways.  *b) Evidence of local arrangements and written clinical protocols to ensure that the primary care team have access to healthcare professionals with expertise in faltering growth.*  We would recommend that Lactation Consultants are specified as the Consultant level of health professionals with expertise in faltering growth, in the local arrangements, as all of the many reasons behind faltering growth are mandated in our extensive training. |
| 47 | Lactation Consultants of Great Britain | Statement 3 | Lactation Consultants of Great Britain welcome the inclusion of structured quality measures - evidence of staff training; local arrangements; written clinical protocols; local care pathways and data on how many mothers are provided with support. These are an excellent start.  It is important to collect statistics how many of those supported mothers are recommended to use artificial breastmilk substitutes because of concerns about faltering growth. We would hope that this number would reduce from the initial baseline. |
| 48 | Lactation Consultants of Great Britain | Statement 3 - audience descriptors | LCGB welcomes that ***Service providers*** *(such as maternity services, GP practices, health visiting services and paediatric secondary care services) will ensure that primary care teams are trained to develop a management plan with parents or carers, tailored to the specific needs of the baby or preschool child.*  We would welcome the opportunity for Lactation Consultants of Great Britain to help ensure the highest level of training to health care professionals within secondary and primary care teams in identifying and managing the reversal of faltering growth in babies. |
| 49 | Lactation Consultants of Great Britain | Statement 3 - definitions | Please include Lactation Consultants as an addition to the list of ***Healthcare professionals with expertise in faltering growth.*** The qualification is above and beyond baby feeding specialists. While some baby feeding specialists may indeed be fully qualified International Board Certified Lactation Consultants, the majority have not been through the rigorous training and 1000+hours of clinical experience and ongoing continuous professional development required to qualify and re-certify five yearly as an International Board Certified Lactation Consultant.  While all of the other professions listed may be relevant for growth faltering after the first few months, consultant paediatricians are not trained as lactation consultants, nor are paediatric dietitians, nor are speech and language therapists, nor are clinical psychologists nor are occupational therapists. The vast majority of faltering growth in the first few weeks is attributable to difficulties in infant feeding rather than underlying conditions not diagnosed at birth. Sadly, not all health visitors or midwives, who have the majority of contacts with new mothers in the first few weeks have received sufficient or highly skilled training in what constitutes effective breastfeeding support, sufficient to turn around faltering growth. GPs receive no training whatsoever, yet they are one of the first health professionals to whom women may turn. It is perhaps not surprising then, that the substitution with artificial milk for breastfeeding is the most common outcome of growth faltering, when the teams involved are not specialists in providing effective breastfeeding support. Not so much ‘faltering growth’, as ‘faltering support’, perhaps.  It could be argued that some of reason for the UK’s many decades of low rates of successful (as opposed to attempted) breastfeeding can be attributed to Lactation Consultants not being included within all NHS maternity and paediatric care pathways. Sweden for example, has employed teams of Lactation Consultants in every maternity hospital and community service, with structured outreach into local community support groups. Their breastfeeding rates, once similar to ours, are now nearly ninety percent at six weeks. Less ‘faltering growth’ in Sweden. |
| 50 | Royal College of General Practitioners | Statement 3 | Can the committee consider adding “when medical causes have been excluded” to statement 3. It is essential for healthcare professions to exclude medical causes for faltering growth (e.g. 10% loss in babies not returning to birth weight by 2 weeks of age or crossing 2 centile lines for 9-91st centile growth). I.e. Babies and preschool children have a management plan with specific goals if there are concerns about faltering growth and medical causes have been excluded |
| 51 | Royal College of General Practitioners | Statement 3 – structure measure b | Whist we accept that this quality statement is the gold standard, it is important to note that due to funding and resource limitations in health visiting services that it is increasingly uncommon for health visitor and GPs to meet regularly or be on the same site. Many health visiting services now directly refer to secondary care and bypass primary care all together. |
| 52 | Royal College of Nursing | Statement 3 - definitions | Page15: “*Primary care team”* – the list should also include:  School Nurses  Children’s Nurses |
| **Statement 4** | | | | |
| 53 | British Dietetic Association | Statement 4 | Health visiting teams are not always adequately trained to support breastfeeding, particularly if time and resource poor. Parents also need more access to education around persisting with breastfeeding. |
| 54 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 | I suggest that this statement is reworded as follows; ‘ Supporting breastfeeding during supplementation with PHDM (pasteurised human donor milk) or artificial formula milk. Rationale: PHDM supplementation is for breastfed babies is recommended by WHO prior to use of artificial formula milk. |
| 55 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 | I suggest that the quality statement is reworded as follows: ‘Mothers are supported to continue breastfeeding and increase their breastmilk supply if their baby is given supplementation with PHDM (pasteurised human donor milk) or formula because of concerns about faltering growth’. Rationale: mothers rarely receive information on how to increase their own milk supply when their babies are being given supplementary milk feeds so that they can aim to return to exclusive breastfeeding. |
| 56 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 | I suggest the rationale is reworded as follows: ‘Breastfeeding is recognised as the best way to feed babies under 6 months because it meets their energy and nutrient requirements and provides the mother and baby with immunological and other benefits. If a breastfeeding baby is given supplementary milk feeds in addition to feeding at the breast because of concerns about faltering growth, the mother should be encouraged to increase her breastmilk supply sufficiently. The mother should be encouraged to supplement her baby with EBM (expressed breastmilk) and when not available PHDM and when not available artificial formula as per WHO recommendations. Ways a mother can increase her breastmilk supply include draining both breasts a minimum of 12 times/day – this can be done by the baby feeding at the breast or the mother expressing. As supplementary milk feeds are usually a short term measure this will help to ensure that exclusive breast feeding can resume in babies up to 6 months old where possible’. |
| 57 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 – structure measure | Suggested rewording of “supplementation with formula is prescribed” to “And supplementary milk feeds have been prescribed”. |
| 58 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 – process measure | Suggested rewording in Process of “supplementation with formula” to “supplementary milk feeds” and in denominator “supplementation with formula” to “supplementary milk feeds”. |
| 59 | Cheshire & Wirral Partnership NHS Foundation Trust | Statement 4 – audience descriptor | Suggested rewording in service providers of “Formula is prescribed” to “supplementary milk feeds are prescribed”.  Suggested rewording in healthcare professionals of “Formula is prescribed” to “supplementary milk feeds are prescribed”. And “before giving the formula” to “before giving PHDM or artificial formula”.  Suggested rewording in healthcare professionals as follows: “This includes, for example, encouraging them to feed their baby with any available breast milk before giving PHDM or artificial formula; providing support with positioning and attachment at the breast to ensure the baby is effectively transferring breastmilk; advice on how to express breast milk to promote their milk supply and loaning of breast pumps if needed.  Suggested rewording in mothers of babies with faltering growth: “formula milk” to “supplementary milk feeds”. And “formula” to “PHDM or artificial formula milk”. |
| 60 | First Steps Nutrition Trust | Statement 4 | This statement only suggests supplementation with infant formula and does not suggest that supplementation could be with donor human milk. Research suggests that where donor human milk is given, mothers are more likely to go on to become successful breastfeeders (Wilson et al, 2017; Kair and Flaherman, 2017; Kantorowska et al, 2016). Could the wording change to acknowledge this throughout? In addition, the vague term “formula” should be changed to “infant formula”, as this is a specific product recommended for the first year of life, which is subject to a specific set of regulations  Our suggested changes are: Quality statement 4: Supporting breastfeeding during supplementation with infant formula or donor human milkQuality statement Mothers are supported to continue breastfeeding if their baby is given supplementation with infant formula or donor human milk because of concerns about faltering growth  **In the Rationale**  If a breastfeeding baby is given infant formula or donor human milk to supplement breast milk because of concerns about faltering growth, the mother should be encouraged to feed the baby with her own breastmilk before giving any infant formula or donor human milk and to express breastmilk to promote their milk supply. As supplementation with infant formula or donor human milk is usually a short term measure …….  And appropriate changes to wording throughout the document to include “infant formula” and “human donor milk”.  We would also like to see the following changes.  1. The rationale should better reflect SACN guidance (SACN (2018) Feeding in the First Year of Life), i.e. Exclusive breastfeeding is recognised as the optimal feeding mode for infants under 6 months and breastfeeding is recommended to continue to at least 12 months.  2. We would like to see the last sentence read ‘As supplementation with infant formula or donor human milk is usually a short term measure, this will help to ensure that exclusive breastfeeding can resume in babies up to 6 months old and be continued in the second 6 months and beyond.  3. As per 1.1.7 in NG75 (and the quality statement itself), if a breastfed baby is given infant formula (or donor human milk) to supplement breastmilk because of a concern about faltering growth, the priority action is to **support the mother to continue breastfeeding**. The current wording is confusing and fails to make this emphasis, instead focusing on ‘feeding of breastmilk’ which is subtly but importantly different.  4. In ‘structure’ and ‘data source’ (page 17), explicit reference should be made to the persons suitable to provide breastfeeding support; suggest **‘infant feeding specialist’** which usually includes specialist lead midwives and health visitors who have received additional training.  5. In ‘what the quality statement means for different audiences’ the text on health care professionals should be edited to better acknowledge that the persons suitable to provide breastfeeding support will be those with additional training, making them **‘infant feeding specialists**’.  6. On page 19 change the term from “formula milk” to “infant formula”. Infant formula is unlikely to be prescribed but to be given, so could this change to clinically recommended, as follows:  **Mothers of babies with faltering growth** are encouraged and helped to continue breastfeeding their baby when infant formula has been clinically recommended to supplement breastmilk.  References:  Wilson E et al (2017). Room for improvement in breast milk feeding after very preterm birth in Europe: Results from the EPICE cohort. Maternal and Child Nutrition, 14(1), e12485 (<https://onlinelibrary.wiley.com/doi/full/10.1111/mcn.12485>)  Kair LR, & Flaherman, VJ (2017). Donor Milk or Formula: A Qualitative Study of Postpartum Mothers of Healthy Newborns. Journal of Human Lactation, 33(4), 710-716. (<https://journals.sagepub.com/doi/10.1177/0890334417716417>)  Kantorowska A et al (2016). Impact of Donor Milk Availability on Breast Milk Use and Necrotizing Enterocolitis Rates. Pediatrics, 137 (3), e20153123. (<https://pubmed.ncbi.nlm.nih.gov/26908696-impact-of-donor-milk-availability-on-breast-milk-use-and-necrotizing-enterocolitis-rates/>) |
| 61 | Lactation Consultants of Great Britain | Statement 4 | **Quality Statement 4** – “*Expressing milk to promote milk supply”*- is only one way to encourage more milk production. Expression of milk by itself will not address the cause of low milk supply if caused by a history of poor milk transfer and that cause is not corrected. There may also be several other contributing factors.  *Highly* skilled assessment of attachment and milk transfer should be provided within an infant feeding care pathway. (After all, if *highly* skilled support had been made available, then growth faltering is much less likely to have arisen in the first place.) We would recommend that this emphasis on highly skilled assessment should be included within the guideline. Helping the mother to make some adjustments to improve milk transfer may be all that is required to prevent or reverse growth faltering. Identifying those adjustments is a true skill.  This assessment and skilled support should be provided ideally *before* any artificial milk is prescribed, and prevent the need.  Lactation Consultants are the ideally qualified health professionals to provide this service and to train any other health professionals involved in a mother and infant’s care. These skills should be sought out, treasured and ring-fenced against any cuts within community and hospital services. |
| 62 | Lactation Consultants of Great Britain | Statement 4 – structure measure | *Structure* *Evidence of local arrangements to ensure that mothers receive practical support to continue breastfeeding if there are concerns about faltering growth if supplementation with formula is prescribed.*  LCGB welcomes this seeking out and documentation of evidence of mothers receiving practical support, particularly if supplementation with formula is prescribed. |
| 63 | Lactation Consultants of Great Britain | Statement 4 - measure | *Local data collection, for example local care pathways for midwives and health visitors to provide support to breastfeeding mothers, breastfeeding support staff numbers and availability* LCGB welcomes this seeking out and documentation of evidence of breastfeeding support staff numbers and availability. |
| 64 | Lactation Consultants of Great Britain | Statement 4 – process measure | *the number of breastfeeding mothers whose baby is given supplementation with formula because of concerns about faltering growth* LCGB welcomes this seeking out and documentation of evidence of breastfeeding mothers whose baby is given supplementation with formula because of concerns about faltering growth |
| 65 | Lactation Consultants of Great Britain | Statement 4 – audience descriptor | ***Service providers******and Commissioners*** *(such as clinical commissioning groups and local authorities, as well as maternity services, GP practices and health visiting services)*  LCGB welcomes the initiative to ensure that sufficient numbers of staff have the expertise to provide support and that the support is provided quickly to reduce the risk of the mother stopping breastfeeding and that other support, such as loaning breast pumps, should also be given. |
| 66 | University Hospitals Birmingham | Statement 4 | There should be some mention of infant feeding advisors and breast feeding support professionals |
| **Additional areas** | | | | |
| 67 | Lactation Consultants of Great Britain | Additional area | In terms of quality improvement, it would be helpful to see skilled assessment of tongue-tie spelled out within these guidelines. There has been a marked rise, not simply in diagnosis but also occurrence of tongue-tie in the last thirty years, possibly associated with increased use of folic acid (an artificial form of natural methylfolate) in pre-pregnancy or early pregnancy.  Supportive reference here; published last month in January 2020:  <https://www.ncbi.nlm.nih.gov/pubmed/31835174>  Amitai, Y., Shental, H., Atkins-Manelis, L., Koren, G. and Zamir, C. (2020). Pre-conceptional folic acid supplementation: A possible cause for the increasing rates of ankyloglossia. *Medical Hypotheses*, 134, p.109508.  Tongue tie is a recognised and frequent contributor to failure to thrive in breastfed (and bottle fed) infants. It is usually associated with severe pain for the breastfeeding mother and poor milk transfer despite an initially abundant milk supply, that can be inhibited later due to significant amounts of milk remaining in the breasts. Too many mothers’ concerns are still being dismissed even when tongue tie had been noted by health care staff on the delivery suite, but with a ‘watch and wait’ principle. This ‘waiting’ without continuity of care and/or also watching daily and swiftly remedying - often leads to growth faltering and considerable physical and emotional distress for the mothers and their babies until the tongue tie is treated. Some babies are switched to bottle feeding, with or without health care practitioner guidance. This does not solve the problem, and often compounds the delay to resolution, when it is found that the baby cannot drink expressed or artificial milk from a bottle either. By that time, the breastfeeding journey has often been disrupted or lost completely. The NHS then has to pick up the bill for another baby with avoidable health impacts due to the artificial feeding that was absolutely not the mother’s original choice for her infant or herself.  Below is an extract from an article on the genetic polymorphisms behind the issue. Although the emphasis is on preventing anaemia and lowering homocysteine levels, the mechanisms of folic acid conversion or l methylfolate are the same. These mechanisms also have potential impacts contributing to ankyloglossia and other midline defects such as foreskin issues:  Greenberg, James A, and Stacey J Bell. “Multivitamin Supplementation During Pregnancy: Emphasis on Folic Acid and l-Methylfolate.” *Reviews in obstetrics & gynecology* vol. 4,3-4 (2011): 126-7.  About 40% to 60% of the population has genetic polymorphisms that impair the conversion of supplemental folic acid to its active form, l-methylfolate.  In vivo, the body converts dietary folic acid to l-methylfolate through a series of enzymatic processes. The final stage is done with the enzyme methyltetrahydrofolate reductase (MTHFR). Those with certain polymorphisms have inadequate MTHFR activity. Based on the high prevalence of these genetic polymorphisms and the importance of assuring that pregnant women get adequate folic acid, supplementation with l-methlyfolate may be the best option to avoid blood folate deficiencies. At present, it is not practical to test every woman to see if they have the relevant polymorphisms. My advice is to prescribe prenatal vitamins containing l-methlyfolate instead of folic acid for women with a family history of NTDs or preterm births. Other women can use prenatal vitamins containing folic acid. However, there is preliminary evidence that l-methylfolate may be useful to prevent postpregnancy anemia. In contrast with women who used a prenatal product that contained folic acid, those who had l-methylfolate in their prenatal supplement had significantly higher hemoglobin levels at the end of the second trimester (P < .011) and at delivery (P < .001). Based on this study, it appeared that women benefitted from l-methylfolate in their prenatal vitamin in terms of having a lower incidence of anemia.  Training tool for more consistent assessment of ankyloglossia available:  Ingram, J., Copeland, M., Johnson, D. and Emond, A. (2019). The development and evaluation of a picture tongue assessment tool for tongue-tie in breastfed babies (TABBY). *International Breastfeeding Journal*, 14(1). |
| 68 | Lactation Consultants of Great Britain | Additional area | In addition, LCGB would recommend that the re-establishment of mothers’ milk banks should be encouraged in all communities, in the same way as human blood banking and transfusion services. Human milk should be available to all mothers who wish to provide human milk exclusively to their infants, while they are building up their own supply.  This option is not yet mentioned in the guideline, and is an omission. Banked human milk donated by other mothers is a much safer option than artificial breastmilk substitutes (formula); and is recommended by the both the World Health Organisation and UNICEF. |
| 69 | Royal College of General Practitioners | Additional area | This document focuses on feeding and eating when faltering growth is identified. It is essential that the health care professional considers other causes for faltering growth, including infections and medical conditions which is currently absent from the quality standard. |

## Registered stakeholders who submitted comments at consultation

* British Dietetic Association
* Cheshire & Wirral Partnership NHS Foundation Trust
* Child Growth Foundation
* Coeliac UK
* First Steps Nutrition Trust
* Lactation Consultants of Great Britain
* Oxford Health NHS Foundation Trust
* Royal College of General Practitioners
* Royal College of Nursing
* Royal College of Paediatric and Child Health
* Royal College of Physicians
* UK National Screening Committee
* University Hospitals Birmingham