NICE Clinical Guideline:

Faltering growth

Stakeholder scoping workshop notes

Presentation
The group was welcomed to the meeting and informed about the purpose of the day. The group was informed that the stakeholder scoping workshop is an opportunity for stakeholders to review the draft scope and give their input into whether it is clinically appropriate. The group received presentations about NICE's work, the work of the National Collaborating Centre for Women's and Children's Health (NCC-WCH) and the work of the patient and public involvement programme. The Chair of the guideline committee also presented the key elements of the draft scope.

Scope
Change of title from Failure to thrive to Faltering growth
Group 1 There was general agreement on the proposed title change to 'Faltering growth'. The group noted that this is the commonly used term in current clinical practice. It was suggested that 'faltering growth' might unduly emphasise medicalisation and that 'thriving' was a broader concept encompassing behavioural and psychological development. However, it was agreed that this was too broad a concept for a single guideline to address and focussing on physical growth was sensible. **Group 2** The group agreed with the change of title to 'Faltering growth' as this is an accurate view on what is being measured and felt that the term 'failure to thrive' was negative. The group raised that GPs may not have heard of the term faltering growth, however it is often used as an outcome in clinical trials and therefore other professionals should be familiar with the term. The group felt that the term faltering growth needed to be specified and quantified in the guideline. **Group 3** The group felt that the title should change but felt that 'faltering growth' also had negative connotations. The title 'identification and management of under nutrition in the infant and pre-school child' was suggested as this does not have negative connotations.
General Comments
Group 1 The group felt that there was potential for overlap with and cross-referencing to existing public health guidance.

Group 2
No comments

Group 3
The group discussed whether or not emotional development should also be included but realised that there was not much evidence for this and this is linked to factors other than calorie intake.

The group pointed out that some families are only supported by volunteers and do not have any contact with healthcare professionals so the guideline should include recommendations for them. The group were in agreement that consistent advice to volunteers would be important.

Section 1.1 Who is the focus? - Population

Group 1
The group noted that there was considerable variation in screening and felt that some children would be missed from the guideline population as they were not being 'routinely' monitored. The group felt it was crucial to define what is meant by 'routine monitoring' either in this guideline or elsewhere and that recognition of faltering growth could not be adequately covered without this.

The group felt strongly that children with specific disorders should be included, but that the management of the disorder itself could be excluded.

Group 2
The group agreed with the population, but raised concerns that specific disorders may not be covered in the diagnostic part of the guideline.

Group 3
The group felt that excluding all children with other conditions could be harmful.

They also felt that children with intrauterine growth restriction should be included.

Equalities

Group 1
No comments

Group 2
The group raised that Asian communities sometimes feed infants exclusively on milk for longer periods of time which might be nutritionally significant.

They felt that restricted diets may be more common amongst high socioeconomic groups, for example, believing children are allergic to specific food.

The group felt that there should be some recognition of the needs of parents with learning disabilities.

Group 3
The group felt that parents from low socioeconomic groups may be assumed to be at increased risk of having a child with faltering growth. Child neglect might also be considered a likely cause of faltering growth. Neither of these are necessarily correct assumptions and most parents or carers require support.

The group also felt that looked-after children might be an important group for consideration.

Section 1.3 Management
Key areas that will be covered

Group 1

The group did not have any suggestions for areas to remove from the draft scope. One stakeholder suggested that prevention of faltering growth could be included but there was no wider agreement on this from the rest of the group.

The group made the following comments on the key areas in the draft scope:

1. **Recognition of failure to thrive**
   No changes were suggested.
2. **Assessment of suspected failure to thrive**
   The group suggested removing ‘suspected’ and ‘occurring in isolation’ as it is important to look at all causes. Risk factors should be moved from this section, possibly to area 1 (recognition). Determining the cause of faltering growth is important in deciding treatment strategies so this is a crucial topic.
3. **Monitoring and follow-up of infants and children with suspected or confirmed failure to thrive**
   No changes were suggested.
4. **Interventions to treat failure to thrive**
   The group suggested changing ‘treat’ to ‘manage’. Breastfeeding should be mentioned specifically, and the group noted that it was important not to discourage breastfeeding. The group felt that it was important to include infant feeding, breastfeeding, weaning, and dietary advice for the baby and the woman in the nutritional interventions reviews. Psychological and behavioural support including infant/child and parental factors should be considered in the family support reviews. There was confusion over the positioning and prominence of the standard text on drug licensing indications and the group suggested that this paragraph could be moved to the end of the section.
5. **Design of services for the management of failure to thrive**
   No changes were suggested.
6. **Information and support for parents and carers of infants and children with failure to thrive**
   The group felt that recommendations in this area should apply to any case where there is concern over growth, not just in those with identified faltering growth.

Group 2

The group agreed with the areas to be included.

Group 3

Group 3 discussed the questions at the same time as the areas to be covered.

1. **Recognition of failure to thrive**
   The group felt that defining failure to thrive/faltering growth is very important and that the definition will be dependent on what the title of the guideline is. They also stressed that thresholds would need to take into account the height of the parents.
2. **Risk factors**
   The group noted that:
   - risk factors can be confounding (separating cause and effect)
   - risk factors can apply to the family and not just the child (for example postnatal depression in the woman, anxiety of the care-giver)
3. **Monitoring and follow-up**
   The group felt that this needs to include who does the monitoring and follow-up as well as what should be done. There was concern that this would need to be in line with the Healthy Child Programme but as these children are not healthy they concluded that this probably would not be the case.
   One individual felt very strongly that current guidance does not recommend

weighing babies frequently enough and that this guideline needs to recommend frequent weighing. However, there was concern in the rest of the group that over-weighing can cause problems.

4. **Interventions**
   The group felt that dietary advice and feed supplementation should be split into two questions as they are different issues.
   They felt that managing parental anxiety needs to be included here (for example, reassurance that sleep feeding will not harm the child).
   They felt that the inappropriate involvement of social services can be harmful in cases of failure to thrive.
5. **Design of services**
   The panel discussed that this could include when to give information as currently parents have to wait a long time for treatment but are then advised, for example, to complete a food diary, resulting in an unnecessary delay which could be avoided. This should address whether there is a need for feeding clinics and if so what they should do.
6. **Information and support**
   The panel felt that the question should remove the words parents/carers so that everyone who might be feeding a child is included.
   They also felt that information on correct portion size would be useful.

Areas that will not be covered

Group 1
The group felt that this should be amended to clarify that the management of specific disorders causing faltering growth would not be covered, but that recommendations on the management of the faltering growth itself might still apply to children with a diagnosed disorder. Cardiac problems were given as an example where management of the underlying problem would be out of the guideline scope, but advice on managing the resulting inadequate growth would still apply.

Group 2
The group agreed with the areas that will not be covered.

Group 3
The group felt that if specific conditions were to be excluded then they should be named conditions as advice in this guideline could be applicable to some children with other conditions.

Section 1.6 Main Outcomes

Group 1
The group felt that all outcomes should be considered in the short, medium and long term, as the impact of inadequate growth is often not obvious early on. In particular, the emphasis should be on long-term health rather than short-term weight gain. Mental health should be included, and admission to hospital could be removed as it is not specific enough. Health-related quality of life should be considered for both children and families. Adherence to interventions was not felt to be worded correctly – the group suggested changing this to usability or acceptability of interventions. The group felt that the outcome ‘patient/carer perspective’ should be included but did not provide further detail on how this might be measured.

Group 2
The group raised concerns that there may be several reasons for lack of adherence to interventions, for example, in children with regurgitation. This should be taken into consideration.
The group felt that head circumference should be included as an outcome as this is a

common method of monitoring development.
The group felt that the health related quality of life scales should include mental wellbeing.

Group 3
The group felt that improved feeding or going from tube to oral feeding should be included as outcomes.
One member of the group did not feel that admission to hospital should be an outcome but the rest of the group disagreed with this.

Section 1.5 Key issues and questions

Group 1
The group felt that the question 'What is the role of specific disorders in the development of failure to thrive in the absence of other clinical manifestations?' was confusing. They suggested several alternatives:

- What is the incidence of faltering growth in children with no other symptoms?
- What is the risk of not investigating in faltering growth with no other symptoms?
- What is the role of medical investigation in faltering growth with no other symptoms?
- When should investigations for specific disorders be carried out in children with faltering growth?

The group thought that there would be a lot of evidence in this area, in particular an American algorithm for identifying feeding difficulties which outlined when and how to investigate for underlying disorders.

The group felt that the questions on interventions for faltering growth should include social care interventions, and could be restructured to focus on the target of the intervention.

There was a suggestion that the question on service design should include community based caseload midwifery.

Group 2

1. **Recognition of failure to thrive**
   The group felt that it would be useful to include which tools are most effective, for example, breastfeeding assessment, growth charts and the inclusion of a 'red flag' chart to inform professionals.
   Thresholds for concern should be specified, for example borderline rates of weight gain.
2. **Interventions to treat failure to thrive**
   The group felt that the risks and benefits of interventions should be considered. The indications for contacting other professionals in cases where there is no identified condition but faltering growth should be considered.
   The group noted that currently there is a marked variation in current practice between services.
3. **Design of services for the management of failure to thrive/Information and support for parents and carers**
   The group emphasised the importance of timing of information-giving, so parents do not feel overloaded.

Group 3
Group 3 discussed this when discussing the key areas.

Other key points

Group 1
The key points reported back to the wider workshop were as follows:

1. the guideline title should be changed
2. reviews should focus on the assessment of long-term health benefits/harms
3. children with specific diagnosed disorders should be included
4. risk factors for faltering growth should be moved to the key area on recognition.

Group 2
The group felt that there is a link between this guideline and the Gastro-oesophageal reflux disease guideline.

Group 3
The key points reported back to the wider workshop were as follows:

1. the guideline title should be changed
2. some children with other disorders should be included in the scope
3. children with intrauterine growth restriction will be an important subgroup.

Guideline committee composition

Proposed members

Group 1
The group did not suggest removing any of the proposed guideline committee members.

Group 2
The group felt that the professional with expertise in breastfeeding should be a midwife.

Group 3
The group did not suggest removing any of the proposed guideline committee members. They were very pleased about the inclusion of a breastfeeding specialist.

Members that should be included

Group 1
The group suggested including the following additional full members:

- a social worker with experience in faltering growth
- an occupational therapist (possibly as an expert witness).

The group suggested including the following expert witnesses:

- a cardiac specialist (for the review on the causes of faltering growth)
- a gastroenterologist (for the review on the causes of faltering growth).

Group 2
The group proposed the following members as expert witnesses:

- social worker
- psychologist
- paediatric nurse
- specialist in breastfeeding clinic/outreach clinic.

Group 3
The group suggested the addition of a second dietitian and an occupational therapist.