NICE Clinical Guideline:

Specialist neonatal Care

Stakeholder Scoping Workshop

14th December 2016

Introduction and presentations

The group were welcomed to the meeting and informed about the purpose of the day. 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 Guideline Alliance (NGA). The Clinical Lead of the guideline committee also presented the key elements of the draft scope.

Following questions discussion was held around the key issues.

Scope

General Comments

The Stakeholders were invited to make general comments on the scope of the guideline and points included:

- Discussion on the referral and Department of Health (DH) expectations and the Care Quality Commission (CQC) document, and the reasoning behind focusing on respiratory disorders.
- It was commented that the CQC document focused on 1 specific case on identifying and managing fetal anomalies and neonatal hypertension and long term respiratory support in community.
- A number of stakeholder representatives suggested that it was important for the guideline to consider the parental perspective and that the guideline should be developed from the babies' perspective.
- Stakeholder representatives were asked what they felt about the decision to focus on respiratory disorders, the alternatives available and their rationale. Overall the focus of respiratory disorders was agreed an area to be of importance.
- A stakeholder representative felt it was important to know the precise remit from the DH as specialist neonatal care is a wide speciality. The meeting was informed that the remit letter reported that NHS England wanted the following areas to be included in the guideline scope:
  - Discharge pathway from hospital to home
  - Caring for infants and children who require long term ventilation
- There is a plethora of services involved in specialist neonatal care and the linking to community and the discharge pathway, is not just limited to respiratory issues. Further clarification was provided that the steer from the DH in the remit letter was to include 'assessment of airway' as one of the clinical issues in the guideline and that a lot of home care involves respiratory issues.
- It was noted that the scope did not include feeding issues and that this was an important

area as it is imbedded in babies with respiratory problems, and important in discharge. Two separate groups were mentioned: home ventilation versus discharge planning. It was noted that the NICE guideline on postnatal care covered feeding. However, some stakeholders noted that the feeding needs in the population covered by this guideline are different, as expert input is required for preterm babies with respiratory issues (including long term feeding and speech and language). As a result, some stakeholder representatives commented that it was important to capture the multidisciplinary needs of the groups covered in the scope, including the family/patient perspective is important.

- There was concern that transport issues were excluded from the draft scope. For example, it was mentioned that lung damage can occur during transport of the infant.
- A stakeholder representative noted that that long-term ventilation is done by paediatric nurses and it would be important to highlight this. The group were informed that NICE clinical guidelines usually says what should be done rather than who should do it.
- Another stakeholder representative noted the importance of considering expertise rather than job titles.
- Resource implications was raised as a possible concern from the recommendations in the guideline, for example if they specified that certain types of care could only be provided in certain settings. A Transformation Review (of neonatology) is currently being undertaken and there was concern that the guideline may recommend a difficult service plan. The group were informed that NICE considers resource impact and that recommendations with a cost impact of greater than £1 million would have to be supported by good evidence of their cost-effectiveness.
- A stakeholder representative felt there are two clear pathways (one acute care and one domiciliary care pathway) and wondered whether it would be better approached as two separate guidelines. The difficulty with this approach is that there would be a risk that one may not be commissioned.
- Discussion was held on the general issues around long-term development, their importance and the impact on outcomes. It was suggested that intervention rather than follow-up was the focus of this guideline. The importance of feeding in hospital and community settings was raised again. Stakeholder representatives stressed the importance of developmental outcomes in the neonatal period noting that family input is essential at this time. It was felt that neurodevelopment support should be given alongside respiratory care and that this is often overlooked. Development and progress should be at the core, putting baby at the forefront as this is all part of specialist neonatal care and not one thing should be taken in isolation. It was therefore suggested that the guideline needed to focus on holistic care and not take a narrow clinical perspective. In the context of this discussion it was noted that a NICE guideline on the Developmental follow-up of Preterm Babies is currently in development.

Section 3.5 Key issues and questions

Issues that will be covered

The Stakeholders discussed the review questions and the main points were:

- Clarification is needed for question 1.1 in that it should read ‘after birth’ not ‘at birth.’ A stakeholder representative asked if the guideline would cover antenatal issues.
- There was some discussion about appropriate terminology particularly with respect to bronchopulmonary disease (BPD) and chronic lung disease. The workshop agreed that terms needed to be used consistently.
- Would the guideline be covering the transfer from delivery suite to unit or only transfer

from the unit to home? There was discussion on issues around getting cold and surfactant production and parental involvement.

- Clarification was sought on what value the risk factors topic would have. Examples were given about getting cold and stopping antibiotics, and how these might help with diagnosis. For example, pneumonia is a risk factor fever, if pneumonia is excluded as a diagnosis antibiotics must be stopped immediately. It was noted that 2.1 and 2.2 are large review questions. Also, it was stressed that there are many anomalies that is not specified at this point but nevertheless they should be considered when reviewing the questions.
- There are 7 parts to question 2.1 and 2.2, and it was felt another one should be added about environmental management (temperature regulation etc.).
- It was noted that for some conditions over/under ventilation can cause problems; also the effects may be different for the same baby on a different day.
- It was noted that 3.2 has a mixture of patient needs and a mixture of treatments including holistic management. A stakeholder representative asked for clarification as to whether corticosteroids at the antenatal stage were being included. In response it was noted that this was covered in the NICE guideline on Preterm birth.
- Would the guideline cover anaemia issues for babies on ventilators i.e. when to transfuse? It was noted that there is recent guidance available but this is not NICE accredited (British Association for Blood Transfusion). Also, there is disagreement about best practice in this area.
- Discussion about whether the area being covered in question 4 is correct. It was suggested that 2.2 informs this question. It was suggested that we keep 4.3 but that we could remove 4.1 and 4.2 as these questions would fall out of 2.2 and perhaps use 'development of BPD' as an outcome?
- A stakeholder representative felt that question 4.3 is limited to patients/carers at home and should this also consider the neonatal unit? Discussion was held on the importance of empowering the patient/carer through education etc. within the unit which will impact on the home management.
- It was commented that discharge planning and home management may be condition specific
- Discussion was held about specific groups requiring machine ventilation and not discharged direct from unit. Some babies will be transferred to the paediatric unit and then discharged home with follow-up by respiratory paediatricians. There was concern that this group often get lost in the system and require long-term support for developmental problems etc. This area needs to be patient led and not service led. Also, some babies may be discharged to other places other than home e.g. hospice; and that it is important to consider these other settings. The discharge can be similar and expectations can be similar (e.g. how long they may live). Respiratory support can be the same but with hospice/palliative input.
- A stakeholder representative queried what is meant by 'information'? as support is so much more than that, particularly when taking a babies perspective. Clarification is needed as 4.3 says support and that it is different to information. It was felt that support is about being a partner in the babies care and that parental intervention is different to information.
- Discussion was also raised on the importance of providing support to the parents of infants who need to make decisions about when to ventilate or when to turn off the ventilation.

- There was a discussion on the meaning of information. It was noted that it should not be

only leaflets, giving information; but it also should be about enabling parents to learn about the baby's medical condition and the needs and actually being able to take time off.

Section 3.6 Main Outcomes

The following terms were suggested as additional outcomes:

- Death
- Consider 'long term respiratory outcome'.
- Suggestion that 'growth' was an important outcome.
- Incidence of patent ductus arteriosus (PDA) but it was thought this might be relevant to a particular review protocol.
- Mortality and how there are different definitions for death (e.g. early peri-neonatal or extended perinatal, infant mortality).
- It was noted that in terms of hospital stay it was important that the guideline try to cover the fact that it might not necessarily be in the same place.
- Positive outcomes e.g. recovery or 'reduced incidence of re-admission.'
- Important to reflect the involvement of babies care not just patient/carer experience.
- Avoidance or preventable mortality e.g. survival.

Other issues

Ethical issues related to ventilation were also raised. For example, sometimes parents request ventilation when not clinically advised.

Guideline committee composition

Proposed members

Stakeholders made the following points about the proposed membership of the guideline committee:

- Perhaps clarify the pharmacist as having neonatal expertise
- Cardiac surgeon to be removed as this would be covered by the cardiologist.

Members that should be included

- The stakeholder groups each proposed other possible committee members:
- Respiratory paediatrician +/- community paediatric nurse
- Speech and language therapist
- Developmental specialist
- Long term ventilation nurse