# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| BLISS | General | General | Overall Bliss is very concerned about the mis-match between the title and contents of this guideline.<br><br>As it currently stands, the title of this guideline is misleading and inaccurate. The content of the guideline appears to be focused on the management of specific respiratory conditions in infants which begin in the labour ward, and then on the complex pathway they may follow through paediatrics and out into the community post-discharge, rather than on the whole spectrum of 'specialist neonatal care.'<br><br>It is particularly noticeable that the guideline itself references two care settings at the beginning and end of the care pathway – "Early respiratory management after birth and before arrival in the neonatal unit" and "…service models for infants…who continue to need such support including home care" – which are explicitly not delivered in the neonatal unit.<br><br>If this guideline is therefore primarily intended to be about assisted ventilation, or specific respiratory management which starts on the neonatal unit and is then managed by community and/or paediatric services, it must be not only re-named but also clarified as such within a tighter and more defined scope.<br><br>At the very least, it is essential that the title of this guideline is changed from the current 'specialist neonatal care' to more accurately represent its contents, and avoid the misleading representation that the guideline is relevant for the broader spectrum of activity covered under such a heading.<br><br>In the meantime we have included specific comments below line-by-line on the guideline as it is currently drafted. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| BLISS | 2 | 9-11 | This should reference the NHS England / NHS Improvement ATAIN (Avoiding Term Admissions Into Neonatal units) programme, which has shown that over 50 per cent of admissions to neonatal care are of term babies (further information can be found here | Thank you for your comment. The scope has been revised to focus on respiratory support of preterm babies. |

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## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | https://www.england.nhs.uk/patientsafety/re-act/red-term-ad/ and here https://improvement.nhs.uk/resources/reducing-admission-full-term-babies-neonatal-units/). | The admission of term babies to neonatal care is being addressed by the ATAIN work stream and we do not wish to duplicate this work. |
| BLISS | 2 | 25-27 | The CQC review highlighted was based on a single case, and while important lessons need to be learned from it, the rarity of the condition identified make it unsuitable to be the basis of a whole NICE guideline. While the review outlined the need for further guidance on respiratory support in the community for babies discharged home, the management of this actually takes place outside of specialist neonatal care. | Thank you for your comment. The scope has been revised to focus on respiratory support of preterm babies up to and including their planning for discharge and thus the focus is now on neonatal care. |
| BLISS | 2 | 2-3 | It is important to note that transient tachypnoea and meconium aspiration syndrome, which are more common in term babies, will not necessarily result in admission to the neonatal unit. In many instances these will require respiratory management immediately in the delivery suite, with ongoing care provided in a transitional care setting or post-natal ward. | Thank you for your comment. The scope has been revised to focus on respiratory support of preterm babies on a neonatal unit up to and including planning for their discharge, and will therefore not cover these conditions in term babies. |
| BLISS | 2 | 23-24 | As a guideline which is focused on respiratory management it is unclear why this section includes reference to a guideline on transfusion, which is of limited relevance. | Thank you for your comment. We have removed the reference to this guideline on transfusion. |
| BLISS | 3 | 5-6 | Bliss would recommend this sentence is amended to read:<br><br>"Neonatal intensive care units (NICUs) will often be responsible for babies who have more complex problems and need intensive care, but will also provide all levels of care to babies born within their local population and need neonatal admission for any condition." | Thank you for your comment. We have amended this sentence to refer to neonatal intensive care units (NICUs). We have not provided more detail on the use of NICUs for other levels of care as the rest of the scope refers to 'neonatal units' in general. |

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## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | This is to reflect the fact that NICUs do provide all levels of neonatal care, and the majority of babies cared for in these units will not enter at intensive care-level, but instead will be admitted requiring high dependency or special care (and will therefore be from the neonatal unit's own more local geographical catchment area). | |
| BLISS | 3 | 5 | 'Tertiary centres' to be renamed 'neonatal intensive care units' as this is accepted current terminology | Thank you for your comment. We have amended this as suggested. |
| BLISS | 3 | 13 | Change to 'parents and carers of babies admitted onto the neonatal unit'. It is vital to note that 'children' cannot be admitted to neonatal units. | Thank you for your comment. This has been amended to 'babies' as suggested. |
| BLISS | 4 | 1-10 | At this point the scope of the guideline narrows significantly. As mentioned above in point one, the name must be changed to reflect that this is a guideline for managing respiratory conditions in the neonate; and/or the scope of the guideline needs to be significantly changed and clarified. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. |
| BLISS | 4 | 13-14 | End sentence at neonates, or change 'neonates' to babies to be more accessible to parents using this document. Children are not admitted onto neonatal units. | Thank you for your comment. This has been amended to 'babies' as suggested. |
| BLISS | 5 | 21-23 | Comprehensive discharge planning should be undertaken for all babies being discharged from the neonatal unit – not just those who have had respiratory support in hospital. If this guideline remains focused on this narrow area relating to respiratory conditions, we suggest this is re-worded "The specific aspects of discharge planning required for babies who have had respiratory support in the neonatal unit and need continued support for chronic lung disease, including communication with and transition to the community paediatric team". | Thank you for your comment. The scope has been amended to reflect the discharge planning that will be required for babies who have had respiratory support in hospital (beginning in the neonatal period) and need continued support for chronic lung disease. |
| BLISS | 5 | 19-20 | Bliss would recommend that the statement regarding supporting parents is expanded to include "supporting parents and carers to be partners in their baby's care." There is a wealth of evidence which shows the developmental benefits and wider positive impact that high levels of parental involvement have on long-term outcomes for babies admitted to neonatal care, and their families. It is essential that 'supporting parents' is | Thank you for your comment. We have amended the key questions and issues (section 3.5) to include much greater focus on supporting parents to be |

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|---|---|---|---|---|
| | | | not simply equated with giving them information and passing on news. Parents need to be supported to deliver a significant amount of their baby's hands-on care – which can be made more difficult by the presence of ventilation equipment – and must be facilitated to partner with the clinical team in making decisions for their baby. | involved in their baby's care, in partnership with the clinical team |
| BLISS | 5 | 24 | As mentioned above in points one and nine, the title of this scope must be altered if it is not going to cover a large number of topics which make up specialist neonatal care. To keep with the current title and content would be incredibly misleading. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. |
| BLISS | 8 | General | Bliss would suggest a further two questions are added into section 4:<br><br>"4.5: What support should be offered to parents and carers to enable them to be involved in their baby's care, and specifically so they can provide skin-to-skin care and comfort holding to their baby whilst receiving respiratory support?"<br><br>This additional question is extremely important as the presence of ventilation and other respiratory equipment can make it difficult – but not impossible – for parents to provide direct hands-on care and comfort to their baby without significant support.<br><br>"4.6: What practical support should be available to parents and carers to ensure they are able to be close to their baby for the duration of their neonatal stay?"<br><br>This additional question is important for capturing the resources and facilities which must be available to parents to ensure they are able to be with their baby for long, uninterrupted periods of time – these will include accommodation facilities as well as financial support with costs such as travel and meals. | Thank you for your comment. We have amended the wording of these questions to include the involvement of parents and carers in the care of their babies. |
| BLISS | 8 | 18-20 | Bliss would suggest changing this question to read: | Thank you for your comment. We have amended the wording of these questions to include the involvement of |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | "What support should be offered to the parents and carers of babies who need respiratory support in hospital, beginning in the neonatal period to ensure that they are able to be partners in their baby's care and decision making?"<br><br>This would encourage those responding to a consultation on the finalised guideline scope to think beyond just the types of information that are given to parents, and instead what needs to be in place to facilitate and empower parents and carers to be confident in taking the lead in their baby's care and decision making. | parents and carers in the care of their babies, as partners in their baby's care. |
| BLISS | 8 | 24-26 | This question implies written information should be given to parents. To encourage a broader range of answers, Bliss would recommend framing this question around what "information, training and ongoing support" parents and carers will need to receive if their baby is being discharged home with respiratory equipment or complex medication to manage. | Thank you for your comment. We have changed the questions in this section to cover involvement in care, support and information, both while babies are in hospital and on discharge, including in what format the information should be provided. |
| BLISS | 8 | 28 | Bliss would suggest deleting 'and children' from this line as babies are discharged from neonatal services, not children. | Thank you for your comment. We have changed the terminology throughout the guideline to baby or babies, as the age at which they are discharged from neonatal care may vary greatly. |
| BLISS | 8 | 31 | Discharge planning for those on long term ventilation should involve palliative care teams, hospices and community nursing teams, as some babies will be discharged from the neonatal unit into other settings (e.g. hospices or other palliative care settings in the community) rather than home. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. |

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## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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|---|---|---|---|---|
| | | | | This will be cross-referenced from this guideline. |
| BLISS | 9 | 18 | Quality of life should also include location of end of life care that is chosen by the family (where appropriate). | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| BLISS | 11 | 1 | Death needs to be included as an outcome for the pathway | Thank you for your comment. We have included 'mortality' as an outcome and consider this as interchangeable with 'death' |
| British Association of Perinatal Medicine | General | General | The title should be clear this is specialist neonatal respiratory care specifically.<br><br>In recent years, the term lung disease of prematurity is used and is more appropriate in the preterm population.<br><br>The title of this document should change from Specialist neonatal care to Management of respiratory problems in neonates. The focus of the guidance is on the latter domain whilst neonatal care encompasses a large number of other clinical problems/care areas which are not covered by the scope of this guidance and the current title is misleading. The title also clashes with another NICE Guidance – Specialist Neonatal care' with a very different domain. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. The specific management of nutritional support was not prioritised, We will log this issue for reconsideration at the next surveillance point. Parenteral nutrition is being covered in another |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | Respiratory support for babies with respiratory problems is not provided in isolation but is multidimensional including management of poor perfusion, nutritional support etc. It may be more appropriate to focus on Early care of babies with respiratory problems which addresses the full package of care. | NICE guideline which is currently in development. However, this guideline will cover the monitoring of babies receiving respiratory support. |
| British Association of Perinatal Medicine | General | General | Breadth of guideline scope:<br>I would suggest that the existing scope is very broad compared to some topics easily covered by the NICE process. I am not clear as to whether there is sufficient overlap between respiratory disease in the preterm and term infant to justify inclusion of both in this proposed guideline.<br><br>Use of drugs within terms of licensed indications:<br>My own strongly held view is that NICE guidance relating to respiratory support of preterm infants would be hamstrung if it failed to consider whether the licensed dosing and treatment rationales for preterm babies were the best. As simple example is that it is common practise, and may save money, to administer surfactant on the basis of one expensive vial per baby, rather than in dose per unit weight basis. This impacts on decisions about dosing, and also has cost implications. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care of preterm babies. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. The guideline committee will be considering the safety and effectiveness of a number of medicines and will assess the clinical and health economic evidence for their use, which may involve consideration of unlicensed doses. |
| British Association of Perinatal Medicine | General | General | Generally, the scope of this guideline seems too broad and not clearly thought out, with the key areas to be addressed being a very heterogeneous group of problems. There is a mixture of questions for which the answer is known and recommendations are already available, and questions which need to be answered with RCTs – many of these are already in progress or planned. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. The |

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | | guideline committee will focus on the available evidence at the time of guideline development. We recognise that additional evidence is becoming available all the time and that the guideline will need reviewing and potentially updating, in accordance with the NICE schedule for checking that published guidelines are current. |
| British Association of Perinatal Medicine | General | General | It is important that this guidance be developed in conjunction with neonatal, obstetric, midwifery, paediatric respiratory healthcare professionals as well as parents. | Thank you for your comment. We are involving neonatal and paediatric respiratory professionals in the development of this guideline, as well as parents. We will seek specialist advice from obstetric and midwifery professionals if this is relevant for specific areas of the guideline, and feedback from these stakeholders on the draft guideline will be sought |
| British Association of Perinatal Medicine | General | General | The title is misleading and too general. In effect this will look at acute and chronic respiratory conditions in the neonate so should state that.<br><br>I think that patent ductus arteriosus should be taken out of this as it is a cardiac condition that can contribute to pulmonary oedema, rather than a respiratory condition. If it were retained then persistent pulmonary hypertension should not be excluded.<br><br>Otherwise, these respiratory conditions are worth looking at. There is a wealth of RCT and meta analyses available to inform a guideline. | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. We will be including patent ductus arteriosus |

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | It would be important to look at what service effects this guideline might have – the NICE guideline on Early onset Sepsis has had a dramatic effect on increasing neonatal workload, with I suspect little real benefit in outcomes, and a lot of distress to families, despite being well-intentioned. | only in terms of the impact of closure on preventing or alleviating bronchopulmonary dysplasia. Persistent pulmonary hypertension has not been prioritised for inclusion as this is mainly a condition in term babies. The guideline development process will review clinical evidence and the guideline committee will formulate recommendations based on the available evidence, and will also take into consideration health economic aspects which includes the impact on workload. |
| British Association of Perinatal Medicine | General | General | Heading – Specialist Neonatal Care – This is not a scoping exercise on specialist neonatal care. It is purely focused on respiratory and therefore should state this in the title. If I am honest I am glad it is not looking at the entirety of neonatal care as I feel the specialty cannot be reduced to one guideline but in the same breath I feel the same about the respiratory management. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| British Association of Perinatal Medicine | General | General | The scope document describes a respiratory management guideline and therefore it is misnamed. It does not cover enough breadth to live up to its current title (presumably because this would generate a textbook, of which many exist already).<br>Yet, even for a respiratory guideline, it remains too broad in its stated intent (key questions) to be useful in guiding anyone clinically working in a NICU, and would be confusing for any non-clinicians (e.g. parents) to try to use. | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | The implication from the title/content document mismatch is that respiratory management is the root of all ills in babies undergoing specialist neonatal care. This is simply not the case.<br><br>NICE is to commended on prosing guidelines for specialist neonatal care, but in my opinion, tackling the entirety (almost) of neonatal respiratory medicine in one document is an impossible task. Much better that this subject be broken into smaller sections, each of which could easily command a NICE guideline<br><br>The title is incorrect and misleading. It should be called something like 'Specialist neonatal respiratory care'. This is a reasonable focus to have a guideline about, but if it excludes such a massive amount of specialist neonatal care e.g. cardiac, gastrointestinal, nutritional, renal, surgical etc., then the title must be more specific.<br><br>In dealing with respiratory distress, I think the scope should include persistent pulmonary hypertension of the newborn as a cause of/contributor to hypoxia – its diagnosis and associations, its differential diagnosis, its management and treatment in both the term and preterm baby. I could not see any reference to this in the document.<br><br>It will be helpful to clarify if the section of the proposed guideline on "Early respiratory management after birth and before arrival in the neonatal unit" is concerned only with in-hospital transfer from delivery room to neonatal unit? It could be interpreted as including the transport of, say, a 24 week gestation newborn infant from local neonatal unit to tertiary NICU. I'm guessing that the latter isn't the intention, but it might be useful to make that clear. Including transport will substantially increase the complexity!<br><br>I don't quite understand how it will be possible to look at meconium aspiration syndrome (3.3.2) and other term respiratory failure without looking at pulmonary hypertension of | support of preterm babies up to and including discharge planning. Persistent pulmonary hypertension has not been prioritised for inclusion as this is mainly a condition in term babies. The transportation of babies from one unit to another was not prioritised for inclusion, but early care in the delivery room will be included. Meconium aspiration syndrome was not prioritised as it is mainly seen in term babies. |

| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | the newborn. Prompt and aggressive management is essential and this should also include cardiovascular management and vasoactive medication. Respiratory and cardiovascular therapies are inextricably linked in these cases. The same could also be said for management of congenital pneumonia (noted in the same section). | |
| British Association of Perinatal Medicine | General | General | I don't quite understand how it will be possible to look at meconium aspiration syndrome (3.3.2) and other term respiratory failure without looking at pulmonary hypertension of the newborn. Prompt and aggressive management is essential and this should also include cardiovascular management and vasoactive medication. Respiratory and cardiovascular therapies are inextricably linked in these cases. The same could also be said for management of congenital pneumonia (noted in the same section).<br><br>Having listed a broad range of conditions in 3.3.2, the scope has a very limited (aimed at prematurity) list of management goals in 3.5.3.<br><br>We are often concerned that in the appropriate and laudable trend towards non-invasive respiratory support in the preterm infant, there is also a trend towards under management of term respiratory failure which will not be addressed by the scope of this consultation. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. Meconium aspiration syndrome, congenital pneumonia and persistent pulmonary hypertension have not been prioritised for inclusion as these are mainly seen in term babies. Likewise, we will be considering the respiratory support of preterm babies, but not in term babies. We appreciate that respiratory and cardiovascular management are linked but in order to achieve adequate focus on this guideline the guideline committee will only consider evidence relating to respiratory management. We will include both invasive and non-invasive ventilation techniques. |

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## Stakeholder comments table

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|---|---|---|---|---|
| British Association of Perinatal Medicine | General | General | In my opinion, the title is wrong<br>The title is way too broad for the material covered in the guideline specification. Specialist neonatal care encompasses a much wider range of activities than those described here. I would specifically wish to seek assurance from NICE that any quality standards developed from a guideline would not be used to replace existing NICE quality standards relating to the structure of neonatal care, which remain both valid and important in describing the consensus evidential judgement as to how neonatal care should be delivered in the UK.<br><br>I would suggest that a more appropriate title for what is described here would be – management of respiratory disease in neonatal care | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. This guideline will not replace quality standards relating to the structure of neonatal care. |
| British Association of Perinatal Medicine | 1 | 4 | The title suggests a wider scope but the content suggested focuses on respiratory care. Respiratory & cardiovascular care are closely linked in neonatology and one cannot easily separate these physiologies when considering respiratory system and support e.g. managing persistent pulmonary hypertension, or oxygen-ventilation mismatch related to hypotension, poor cardiac output and when managing respiratory function in a baby with a patent arterial duct whose first clue to diagnosis is often a low diastolic BP unless early echocardiography is available.<br><br>The title is incorrect and should surely read "Respiratory Care Guideline" or similar | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. We appreciate that cardiovascular and respiratory care are closely linked, but in order to achieve adequate focus on this guideline the guideline committee will only consider evidence relating to respiratory management. |
| British Association | 1 | 4, 6 | The document states that this will be a guideline on "specialist neonatal care". However, the proposed guideline only aims to encompass one aspect of neonatal care (infants | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on |

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## Stakeholder comments table

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| of Perinatal Medicine | | | needing respiratory support). This document and the proposed guideline need to be more explicit in stating this. | respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| British Association of Perinatal Medicine | 2 | | The comments regarding BPD so closely written to comments regarding term babies is confusing here. A clearer definition of what one is trying to focus on may help. BPD is a disease of preterm infants and the prevention or reduction in severity of that illness requires very different interventions compared to the management of term babies with temporary short-lived respiratory disorders. Perhaps just a little more clarity. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| British Association of Perinatal Medicine | 2 | 25-27 | The CQC review quoted I feel took an unusual line. It is a thorough review with very good lessons but the title suggests it has a broader outlook than it does. It appears to be focused on a very narrow area of our specialty with a focus on hypertension which is a rare problem in neonates. This guideline would have to take care to be badged as what it is and from the outline it looks like a scope on respiratory care. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| British Association of Perinatal Medicine | 2 | 8 onwards | Current practice – Quite correctly this paragraph outlines the variation in practice in respiratory management across the UK. This is a direct result of the lack of evidence with regards to the best strategies and I am concerned that this exercise in guideline production may make recommendations with regards to management that are not based on robust evidence and result in curtailment of practice which is currently within what would be described as mainstream. We cannot have a guideline that looks to restrict variation until we have robust evidence of what is best practice. | Thank you for your comment. The guideline committee will base the recommendations on robust evidence where possible, but will use the experience of the committee members to develop recommendations. |

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## Stakeholder comments table

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|---|---|---|---|---|
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| British Association of Perinatal Medicine | 2 | 21 | These guidelines are now 17 years old, so one would struggle to accept them as current practice. There is no mention of the European Guidelines for the management of respiratory distress syndrome which are updated more recently and valued by many. | Thank you for your comment. We have removed reference to the 1998 guidelines and instead included the European Consensus Guidelines for Respiratory Distress Syndrome. |
| British Association of Perinatal Medicine | 2 | 21 | The inclusion of this guideline is inappropriate, as it clearly states that it is not valid beyond 2002. | Thank you for your comment. We have removed reference to the 1998 guideline and instead included the European Consensus Guidelines for Respiratory Distress Syndrome. |
| British Association of Perinatal Medicine | 2 | 23 | The suggestion of haematology guidelines here suggests a much wider scope than respiratory care – if this is here then perhaps so should nutrition and growth, sepsis, renal function and other wider areas of specialist neonatal care.<br>Again maybe a respiratory care of the term newborn scope is required, and a separate management of the preterm infant specialist newborn care scope is required which would be multi-organ and wider than respiratory care alone. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. We have removed the reference to the guideline on transfusion. |
| British Association of Perinatal Medicine | 2 | 25 | This guidance is for paediatricians with a respiratory interest in the main as neonatology does not usually care for infants on home ventilation and/or tracheostomies. This in the main has a different specialist target audience. | Thank you for your comment. The scope has been revised to focus on respiratory support of preterm babies up to and including discharge planning. Thus we believe that this guideline will be primarily relevant to neonatologists. |

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | However, since it includes discharge planning it will also be relevant to paediatricians with a respiratory interest. |
| British Association of Perinatal Medicine | 3 | 1 | Commissioning:<br>Since 2013, neonatal critical services have been managed within Operational Delivery Networks.<br><br>This is incorrect since the neonatal services have been managed within Clinically Managed Networks since 2003.<br><br>The term 'tertiary centres' should be avoided and the currently accepted unit designations such as Neonatal Intensive Care Unit (NICU) be used. | Thank you for your comments. We believe Operational Delivery Networks is the current terminology for the delivery of neonatal critical care services (https://www.england.nhs.uk/ourwork/part-rel/odn/). We have changed the wording from tertiary centres to Neonatal Intensive Care Unit. |
| British Association of Perinatal Medicine | 3 | 1 | Commissioning and networks:<br>How to address issue of centralising care ( to get better outcomes) vs deskilling workforce in Spcare/LNU | Thank you for your comment. Service delivery aspects - commissioning neonatal care have not been prioritised for inclusion in the guideline. |
| British Association of Perinatal Medicine | 3 | 5 | The key questions read as a 'would like to know' for any neonatologist. However, currently, there is regional, national and international variation in respiratory practice due to the historical evolution of neonatal medicine and the accepted minimum standard requiring RCT evidence/significant meta-analysis to begin to change practice across the board.<br>Good respiratory management is a 'MDT sport' therefore individual NICUs get very good at managing babies in the way that they do. The collective experience of a NICU staff in using a specific type of respiratory staff cannot be underestimated as a factor in that modality's efficacy, yet is unlikely to feature in evidence published. | Thank you for your comments. The guideline committee will base the recommendations on robust evidence where available and will use the experience of the committee members to develop recommendations. We appreciate that more research is needed, but we will focus on the available evidence at the time of guideline development, and the |

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | The risk with the stated scope for the guideline is that it will attempt to define (or worse, be interpreted as) a 'one size fits all' pathway which prevents appropriate educated variation in practice, on a case by case basis, in any unit. The same might also mean that some NICUs feel obliged in the short term to make sweeping changes to practice which could impact survival for a significant cohort of babies for little ultimate gain.<br>The scope questions outlined might also lead to an excess of complaints against units using modalities other than the 'NICE preferred' when there may not be evidence to the contrary (as I doubt the evidence will be strong enough to recommend absolutely any specific mode/machine). This has been seen with other narrow focussed guidance from NICE already (specifically jaundice and sepsis) and if NICE QS is developed from a low grade evidence base this could be problematic.<br>More international research is required to bring the overall evidence base to a position to be able to begin to approach answers to the key questions regarding which techniques of respiratory support are best in what given circumstance.<br>The extension of this guidance to include home respiratory support as a significant section takes the guidance well outside the 'specialist neonatal care' remit and feels like imposition of a specific agenda beyond the implied need for the rest of the document. Home respiratory support in infants and children would, however, be a reasonable separate guideline on which NICE could perhaps more productively focus. | committee may make research recommendations. We recognise that additional evidence is becoming available all the time and that the guideline will need reviewing and potentially updating, in accordance with the NICE schedule for checking that published guidelines are current. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. It will therefore no longer provide detailed guidance on home respiratory support, but will include information on discharge planning for babies who have had respiratory support in hospital (beginning in the neonatal period) and who need continued support for chronic lung disease. We agree that detailed guidance on home respiratory support might be a suitable topic for a separate guideline. |
| British Association | 3 | 11 | The list should include paediatricians specialising in respiratory medicine given the mention of ongoing respiratory care beyond the NNU as many will be cared for jointly. | Thank you for your comment. The scope has been revised to focus on |

| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| of Perinatal Medicine | | | | respiratory support of preterm babies up to and including discharge planning. Thus we believe that this guideline will be primarily relevant to neonatologists. However, since it includes discharge planning it will also be relevant to paediatricians with a respiratory interest. |
| British Association of Perinatal Medicine | 3 | 14 | Guidance on acceptable o2 saturation levels according to gestation and weaning oxygen in community. | Thank you for your comment. Acceptable oxygen saturation levels will be included in this guideline. The scope has been revised to focus on respiratory support of preterm babies up to and including discharge planning so recommendations on weaning oxygen in the community have not been prioritised for inclusion within the scope of this guideline. |
| British Association of Perinatal Medicine | 3 | 16 | Could guidance/evidence on effectiveness and safety of using sildenafil in BPD effectiveness and safety of using steroid inhalers in BPD babies with poor chest symptom control be added? | Thank you for your comment. We will be reviewing the evidence for the safety and effectiveness of corticosteroids in preventing or alleviating bronchopulmonary dysplasia. We will not be considering sildenafil since the treatment of pulmonary hypertension is a condition mainly seen in term babies. |
| British Association | 4 | | Need to standardise O2 sat level monitoring | Thank you for your comment. Acceptable oxygen saturation levels, |

| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| of Perinatal Medicine | | | | and how to monitor them, will be included in this guideline. |
| British Association of Perinatal Medicine | 4 | | Service model for follow up of BPD babies. | Thank you for your comment. The details of a service model for the follow-up of babies with bronchopulmonary dysplasia once they have been discharged from hospital will be outlined in the recommendations the committee make on the safe discharge of babies who have had respiratory support in hospital (beginning in the neonatal period) and who need continued support for chronic lung disease. |
| British Association of Perinatal Medicine | 4 | 3.3 | Key areas that will be covered:<br>Despite a subtitle of Preventing and managing respiratory…., the current list seems to exclude measures aimed at prevention of respiratory problems, especially in late preterm and early term (37-38 weeks' gestation) babies.<br><br>A. The guidance needs to review the current evidence for prevention of respiratory morbidity in these age groups by addressing –<br>a. The timing of delivery especially the trade-off between the risk of stillbirths and risk of respiratory morbidity at these gestations in presence of pregnancy complications such as diabetes, fetal growth restrictions.<br>b. The use of antenatal steroids to reduce the risk of admission to the neonatal unit for respiratory disorders and the risk of bronchopulmonary dysplasia versus deleterious effects such as increased risk of hypoglycaemia, possible adverse neurodevelopmental effects (Gyamfi-Bannerman C, et al. Antenatal betamethasone for | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning.<br>Meconium aspiration syndrome occurs predominantly in term babies and has not been prioritised for inclusion in this guideline. As this guideline will focus on the respiratory support of preterm babies, starting in the neonatal period it |

| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | women at risk of late preterm delivery. New Eng J Med 2016;374:1311-20; Stutchfield P, Whitaker R, Russell I. Antenatal betamethasone and incidence of neonatal respiratory distress after elective caesarean section: pragmatic randomised trial. BMJ 2005;331:662)<br>B. Meconium aspiration syndrome: The guidance should look at ethnically-appropriate gestation cut-off for intervention in view of the evidence of increased risk of adverse perinatal outcomes including meconium aspiration syndrome in women of south Asian and African-Caribbean origin when pregnancy continues beyond 40 weeks (Patel RR, Steer P, Doyle P, Little MP, Elliott P. Does gestation vary by ethnic group? A London-based study of over 122 000 pregnancies with spontaneous onset of labour. Int J Epidemiology 2004;33:107–13;Balchin I, Whittaker JC, Lamont RF, Steer PJ. Maternal and Fetal Characteristics Associated With Meconium-Stained Amniotic Fluid. Obstet Gynecol 2011;117:828-35).). | will not include the antenatal aspects of care (such as antenatal steroids and timing of delivery). |
| British Association of Perinatal Medicine | 4 | 15 | Sec 3.3 - The proposed guideline seems to be aiming to encompass a large area of neonatology. Cochrane reviews, as well as published international and European guidelines, already exist to address many of the "key areas that will be covered" (section 3.3) and "key issues and questions" (section 3.5). Will the proposed guideline be duplicating guidance that already exists? | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. The guideline committee will use existing systematic reviews as part of our evidence base where appropriate to prevent duplication of work, and will consider the content of other guidelines (such as the European update) but will develop guidelines for use in England |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | using NICE processes and methodology which also considers health economics and, may lead to different recommendations than those in existing guidelines. |
| British Association of Perinatal Medicine | 4 | 15 | Sec 3.3; 3.5 - I think the respiratory disorders included should include pulmonary haemorrhage and ventilator-associated pneumonia(VAP). The scope could include the definition, prevention and management of VAP, which is under-recognised in neonates, in part because there is no agreed definition. | Thank you for your comment. Pulmonary haemorrhage and ventilator-associated pneumonia are complications of ventilation and so will be included in the consideration of the effectiveness and safety of different assisted ventilation techniques. |
| British Association of Perinatal Medicine | 4 | 15 | Sec 3.3 - The scope should specify that it will look at oxygen therapy guidance for chronic lung disease as well as for acute respiratory management. This will affect the definitions of chronic lung disease in 3.6 (Outcomes) too. | Thank you for your comment. The scope has been revised to focus on respiratory support of preterm babies up to and including discharge from hospital to home for babies who have had respiratory support in hospital (beginning in the neonatal period) and who need continued support for chronic lung disease. |
| British Association of Perinatal Medicine | 4 | 24 | Sec. 3.3.1 - "1. Early respiratory management (excluding resuscitation) after birth and 25 before arrival in the neonatal unit. This includes oxygen 26 supplementation and assisted ventilation, with: RAFT NICE guideline: Specialist neonatal care draft scope for consultation (12 January to 9 February 2017) 5 of 12 1 • non-invasive techniques (for example high-flow therapy or 2 continuous positive airway pressure [CPAP]) or 3 • invasive techniques (for example conventional ventilation or high- 4 frequency oscillatory ventilation)." | Thank you for your comments. The guideline scope will include respiratory support required after birth, beyond that which would normally be expected to clear lung fluids and transition to spontaneous breathing. However, it will not provide recommendations on the |

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| | | | Use of word "resuscitation" shows that insufficient thought has been given to the development of this guideline. What does this word mean in this context? I could accept that "resuscitation" might refer to efforts to improve a baby's heart rate above 100bpm. However, in the context of pre neonatal unit care of the preterm infant at least (and arguably the term infant) the process of initiating breathing and lung inflation is continuous with "resuscitation".<br><br>If more senior neonatal staff had been involved in the development of this scope, it would have been clear that high frequency oscillatory ventilation is never delivered in pre neonatal unit care. Indeed, there is evidence that little effective CPAP of high flow therapy is used pre NNU in UK practice – although I agree that the latter two therapies should fall within scope. | resuscitation of babies as this is covered by the Resuscitation Council (UK) guideline. We have removed the reference to high frequency oscillatory ventilation before arrival in the neonatal ward, but this will be included in the review of the efficacy and safety of different assisted ventilation techniques. |
| British Association of Perinatal Medicine | 5 | | To exclude PPHN will exclude an important cause of respiratory problems in the neonate | Thank you for your comment. Persistent pulmonary hypertension of the newborn (PPHN) has not been prioritised for inclusion in this guideline as the scope now refers only to babies born preterm and PPHN occurs mainly in term babies. |
| British Association of Perinatal Medicine | 5 | 4 | "Supporting parents and carers, communicating with them and providing them with information"<br>It should be acknowledged that some of these babies will die and that the support offered should also include parallel planning, end of life care and ongoing bereavement care | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| | | | | This will be cross-referenced from this guideline. |
| British Association of Perinatal Medicine | 5 | 4 | Infants who have very significant CLD may need long term ventilation and thus benefit from palliative care services, stressing that this is not to facilitate death but to parallel plan and support parents, respite for parents from children's hospices etc. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| British Association of Perinatal Medicine | 5 | 5 | Sec 2 - The term 'hyaline membrane disease' is a pathological entity diagnosed at post-mortem examination, and should be avoided. | Thank you for your comment. We have removed this term from the scope. |
| British Association of Perinatal Medicine | 5 | 12 | Sec 3 - The medicines list needs to include preventative measures for bronchopulmonary dysplasia such as Vitamin A, | Thank you for your comment. Vitamin A is not widely used and other therapeutic options have been prioritised for the development of this guideline. |
| British Association of Perinatal Medicine | 5 | 18 | Should PDA management be here? There is already a wealth of literature out there proving we do not know what we are doing | Thank you for your comment. We will be including patent ductus arteriosus in terms of the impact of closure on preventing or alleviating bronchopulmonary dysplasia. |
| British Association | 5 | 24 | Failure to thrive is very common among babies with respiratory disorders especially those with bronchopulmonary dysplasia. This has important effects not only on the lung development and maturation but also long-term neurodevelopmental outcomes. Hence | Thank you for your comment. The specific management of nutritional support was not prioritised. We will log |

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# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| of Perinatal Medicine | | | nutritional support of babies with respiratory problem should be addressed in the guideline. | this issue for reconsideration at the next surveillance point. Parenteral nutrition is being covered in another NICE guideline which is currently in development. |
| British Association of Perinatal Medicine | 5 | 24 | Given the exclusions this scope could be retitled to respiratory care on the NNU as it is not specialist care given that there are so many exclusions | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning |
| British Association of Perinatal Medicine | 6 | | The suggestion that NICE guidelines on IV fluid therapy and Gastroesophageal reflux cover neonatal management of these conditions needs amendment. The IV fluid therapy guidance does not reflect neonatal practice and the GORD guideline not very applicable to neonatal practice. | Thank you for your comment. The reference to the IV fluid guidelines has been removed but the NICE clinical guideline NG1 on Gastro-oesophageal reflux disease in children and young people: diagnosis and management (2015) has been left in place as this does include babies born preterm. |
| British Association of Perinatal Medicine | 6 | | Although there NICE guidelines on fluid management and gastroesophageal reflux in children, NG29 and NG1, they do not cover preterm neonates, therefore should be stated as such. | Thank you for your comment. The reference to the IV fluid guidelines has been removed but the NICE clinical guideline NG1 on Gastro-oesophageal reflux disease in children and young people: diagnosis and management |

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## Stakeholder comments table

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | (2015) has been left in place as this does include babies born preterm. |
| British Association of Perinatal Medicine | 6 | | Failure to recognise that guidelines relating to adult experience of care is not applicable to neonatal practice where the whole family needs to be considered and the patient cannot express any views. | Thank you for your comment. We appreciate that the baby cannot express views but feel that the principles of providing good care should still be recognised when caring for babies, and should be included from the parents' and carers' perspective. |
| British Association of Perinatal Medicine | 7 | 9 | Sec 3.5 - There are multiple randomised controlled trials, among them a number of NIHR funded trials either in progress, about to start or planned, which address several of the questions: Early respiratory management, oxygen supplementation, non-invasive respiratory support, postnatal corticosteroids, diuretics, PDA management. It would seem more appropriate to await these results than develop another consensus guideline. | Thank you for your comment. We will focus on the available evidence at the time of guideline development but recognise that additional evidence is becoming available all the time and that the guideline will need reviewing and potentially updating, in accordance with the NICE schedule for checking that published guidelines are current. |
| British Association of Perinatal Medicine | 7 | 9 | Sec 3.5 - The scope definition tries to draw an artificial distinction between resuscitation (we won't look at this) and subsequent respiratory management of babies beginning in delivery suite (we will look at this). For all babies there is a continuum between the two acknowledged within the NLS/ARNI guidance from RCUK and therefore this NICE guidance will inevitably impinge on this area. The NLS guidance acknowledges that the majority of preterm babies (for example) require stabilisation to help transition from intrauterine to extrauterine life rather than resuscitation. It is not clear from the scope how the document will make clear/define the transition point from NLS guidance to NICE guidance in such cases. | Thank you for your comments. The guideline scope will include the respiratory support required after birth, beyond that which would normally be expected to clear lung fluids and transition to spontaneous breathing and will define this. However, it will not provide recommendations on the resuscitation of babies as covered by the Resuscitation Council (UK) |

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# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | guideline, as this would duplicate existing guidance |
| British Association of Perinatal Medicine | 7 | 29 | Sec 3.5.3.1 - This is a question which should arguably be treated as two separate questions, even if the answer is the same to both. The safety profile of oxygen may not be the same, and is certainly not treated by clinicians as the same, in the immediate intensive care period after very preterm birth as opposed to at 36 weeks post menstrual age. | Thank you for your comment. The scope has now been amended to include respiratory support only in preterm babies, but will review the evidence for interventions at different gestational ages. |
| British Association of Perinatal Medicine | 8 | 13 | Sec 3.3.8 - The safety and effectiveness of closure of patent ductus arteriosus should be measured using wider outcomes, especially survival and neurodevelopmental outcomes, and not be restricted to respiratory outcomes alone. For example, interventions that improve respiratory outcomes at the expense of neurodevelopmental outcomes would not be acceptable to the professionals and parents. | Thank you for your comment. We will be including mortality and developmental outcomes and have removed the reference to 'measured with respiratory outcomes' from this question. |
| British Association of Perinatal Medicine | 8 | 16 | Sec 4 - Supporting parents and carers, communicating with them and providing them with information<br>Support could start antenatally where a congenital anomaly is picked up (e.g. diaphragmatic hernias) and support for the whole family should be considered: siblings etc. | Thank you for your comment. The guideline will cover focus on the respiratory support of preterm babies, starting in the neonatal period and will not therefore include antenatal support. Support and information for parents and other family members of babies requiring respiratory support will be included. |
| British Association of Perinatal Medicine | 8 | 31 | Sec 5 - Discharge planning for those on long term ventilation should involve palliative care teams, hospices and community nursing teams, where appropriate. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and |

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## Stakeholder comments table

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| British Association of Perinatal Medicine | 9 | | NEC:<br>Equity of access to donor milk | Thank you for your comment. The management of necrotising enterocolitis (NEC) and the availability of donor milk have not been prioritised for inclusion in this guideline. |
| British Association of Perinatal Medicine | 9 | 6 | Sec 3.6<br>1. These outcomes should also include GROWTH as growth during neonatal period and early infancy has been shown to influence later cognitive outcomes and long-term adult health problems such as diabetes, coronary heart disease etc.<br>2. Many studies of neonatal interventions are now reporting later cognitive outcomes at school age and later, and wherever available these should be included. | Thank you for your comment. We will be looking at developmental delay but we have to limit the number of outcomes we use and have selected those which we think are most important. These will be reviewed when we develop the protocols for each question. |
| British Association of Perinatal Medicine | 9 | 6 | Sec 3.6 - Suggest other outcomes that could be looked at would include long term respiratory outcomes e.g. respiratory morbidity at 2 years, readmission to hospital with respiratory infections e.g. RSV, duration of oxygen therapy in BPD. | Thank you for your comment. We will be looking at acute respiratory outcomes, but we have to limit the number of outcomes we use and have selected those which we think are most important. These will be reviewed when we develop the protocols for each question. |
| British Association | 9 | 11 | Duration of hospital stay:<br>Need for social care in community and 7 day community neonatal nursing | Thank you for your comment. We will be looking at acute outcomes (such as duration of hospital stay), but we have |

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| of Perinatal Medicine | | | | to limit the number of outcomes we use and have selected those which we think are most important. These will be reviewed when we develop the protocols for each question. |
| British Association of Perinatal Medicine | 9 | 18 | Location of end of life care is that chosen by the family | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| British Association of Perinatal Medicine | 10 | | The reference to Endovascular closure of patent ductus arteriosus is inappropriate since this procedure is not performed in the age group focussed in the proposed NICE Guidance. | Thank you for your comment. We will be considering interventions for closing a patent ductus arteriosus only in terms of the impact on preventing or alleviating bronchopulmonary dysplasia. |
| British Association of Perinatal Medicine | 11 | 1 | Death needs to be included as an outcome for the pathway | Thank you for your comment. We had included 'mortality' as an outcome and consider this as inter-changeable with 'death' |
| Chiesi Limited | 2 | 5 | Please consider using chronic lung disease (CLD) which is a general term for long-term respiratory problems in premature babies, which includes bronchopulmonary dysplasia. | Thank you for your comment. We have continued to use the term bronchopulmonary dysplasia as this is |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | more specific to the preterm population which is now the focus of this scope. |
| Chiesi Limited | 2 | 13 | Please consider changing to: Respiratory support is used in different ways in different units, and it is unclear what the best method is for limiting the use of mechanical ventilation and preventing bronchopulmonary dysplasia. [Removal of 'providing']. | Thank you for your comment. We think the term 'providing' covers choice of modality as well as timing of use and that it is more appropriate to use the more general term here. |
| Chiesi Limited | 2 | 18 | Please consider the European Consensus Guidelines for Respiratory Distress Syndrome (Sweet et al. 2016, Neonatology) as a source of information. | Thank you for your comment. We have included reference to the European Consensus Guidelines for Respiratory Distress Syndrome. |
| Chiesi Limited | 2 | 21 | Please note that the Guidelines for good practice in the management of neonatal respiratory distress syndrome from the British Association of Perinatal Medicine are not valid beyond 2002 (as stated on their webpage) and thus not an up to date source of information. | Thank you for your comment. We have removed this cross-reference. |
| Chiesi Limited | 5 | 1 | Both continuous positive airway pressure (CPAP) and high flow nasal cannula (HFNC) are constant airway pressure modes of non-invasive ventilation. Will non-invasive variable airway pressure also be considered, such as nasal intermittent positive pressure ventilation (niPPV)? | Thank you for your comment. We will be considering all applicable modes of invasive and non-invasive ventilation. |
| Chiesi Limited | 5 | 12 | Please consider changing to: Preventing, managing and treating respiratory disorders on the neonatal unit. [Addition of 'treating']. | Thank you for your comment. We consider managing to be a general term that encompasses 'treating'. |
| Chiesi Limited | 5 | 16 | Please consider adding "surfactant administration techniques" as an additional point under 'Preventing and managing respiratory disorders on the neonatal unit'. There is evidence to suggest that there are different outcomes (such as bronchopulmonary dysplasia and CLD) associated with the different surfactant administration techniques (i.e. Standard of Care vs INSURE vs LISA/MIST). | Thank you for your comment. We will be considering the safety and efficacy of surfactant use - this will include administration techniques. |

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# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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|---|---|---|---|---|
| Chiesi Limited | 5 | 25 | Less invasive surfactant administration (LISA) or minimally invasive surfactant therapy (MIST) are less invasive techniques for surfactant administration whilst the infant is spontaneously breathing and therefore avoiding the trauma of mechanical ventilation. The technique uses a thin catheter (instead of an endotracheal tube) to deliver surfactant. It is not clear from the scope whether 'intubation techniques' will include or exclude LISA/MIST.<br><br>There is a growing body of evidence to support the use of LISA/MIST for the treatment of respiratory distress syndrome. There is evidence to suggest that the delivery of surfactant via LISA/MIST reduces the need for mechanical ventilation as well as reducing the composite outcome of death or bronchopulmonary dysplasia in preterm infants with respiratory distress syndrome. In order to support the use of non-invasive ventilation in preterm infants, LISA/MIST should be included. Furthermore, the European Consensus Guidelines for Respiratory Distress Syndrome (Sweet et al. 2016, Neonatology) refer to this technique in their latest guidelines. | Thank you for your comment. We will be considering the safety and efficacy of surfactant use - this will include timing of administration and administration techniques. |
| Chiesi Limited | 7 | 5 | Curosurf® (poractant alfa) 120mg/vial and 240mg/vial are available to the NHS with a nationally available price reduction agreed between the company and the Commercial Medicines Unit. The prices agreed through the framework are commercial in confidence. Please use the reduced prices if economic considerations are relevant.. | Thank you for your comment. If the area is prioritised for economic analysis by the committee we will use national unit costs as reported in the drug tariff/BNF in the base case analysis (as per NICE guidance). However, given that medicines are available to the NHS with a nationally available price reduction we will perform a sensitivity analysis using the reduced unit costs. |
| Chiesi Limited | 7 | 5 | Peyona® (caffeine citrate) 20mg/ml is available to the NHS with a nationally available price reduction agreed between the company and the Commercial Medicines Unit. The | Thank you for your comment. If the area is prioritised for economic analysis by the committee we will use national |

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| | | | price agreed through the framework is commercial in confidence. Please use the reduced price if economic considerations are relevant. | unit costs as reported in the drug tariff/BNF in the base case analysis (as per NICE guidance). However, given that medicines are available to the NHS with a nationally available price reduction we will perform a sensitivity analysis using the reduced unit costs. |
| Chiesi Limited | 7 | 12 | Please note that surfactant delivery can take place in the delivery suite prior to the infant's arrival in the neonatal unit. Surfactant can be delivered prophylactically (before the first breath) or for very early rescue (within 5-15 minutes of birth) for respiratory distress syndrome. Please consider a subsection to address this point. | Thank you for your comment. We will be considering the safety and efficacy of surfactant use - this will include timing of administration and administration techniques. |
| Chiesi Limited | 7 | 28 | Please consider changing to: Preventing, managing and treating respiratory disorders on the neonatal unit. [Addition of treating]. | Thank you for your comment. We consider managing to be a general term that encompasses 'treating'. |
| Chiesi Limited | 8 | 4 | Please consider changing to: what is the effectiveness and safety of surfactant in preventing, managing and treating RDS… [Addition of treating]. | Thank you for your comment. We consider managing to be a general term that encompasses 'treating'. |
| Chiesi Limited | 8 | 4 | Please consider using chronic lung disease (CLD) which is a general term for long-term respiratory problems in premature babies and it includes bronchopulmonary dysplasia. If this cannot be changed, please include CLD in the literature searches. This comment should also be considered for key questions 3.5 – 3.7. | Thank you for your comment. We will develop detailed search protocols for each question to ensure we do not miss clinical evidence that is relevant. We have continued to use the term bronchopulmonary dysplasia as this is more specific to the preterm population which is now the focus of this scope. |
| Chiesi Limited | 8 | 4 | Will the administration of medicines (such as surfactants), or doses available, be considered within this question? | Thank you for your comment. We will be considering the safety and efficacy |

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|---|---|---|---|---|
| | | | For example, less invasive surfactant administration (LISA) or minimally invasive surfactant administration therapy (MIST) are techniques which deliver surfactant via a thin catheter whilst the infant is spontaneously breathing. This technique has been associated with a reduction in the rates of bronchopulmonary dysplasia and a reduction in the use of mechanical ventilation; thus leading to the improvement of longer term outcomes and wellbeing of infants with respiratory distress syndrome. | of surfactant use - this will include timing of administration and administration techniques. |
| Chiesi Limited | 8 | 5 | Please consider changing to: What is the effectiveness and safety of surfactant in preventing and managing and treating respiratory distress syndrome and limiting bronchopulmonary dysplasia? [Addition of treating and limiting]. | Thank you for your comment. We consider managing to be a general term that encompasses 'treating' and 'preventing' to be synonymous with limiting. |
| Chiesi Limited | 8 | 11 | Please note that the licensed indication for the use of caffeine is for the management and treatment of apnea of prematurity and not respiratory disorders and preventing bronchopulmonary dysplasia. | Thank you for your comment. We will be reviewing the clinical evidence for the safety and effectiveness of caffeine in babies born preterm, although this terminology may not match that of the licensed indication. |
| Chiesi Limited | 9 | 6 | Please consider medicine re-dosing when considering the main outcomes outlined in this section. Surfactant re-dosing impacts on clinical outcomes (exposure to invasive procedure and longer need for mechanical ventilation) and economic outcomes (cost of a second dose, longer hospital stay, etc). | Thank you for your comment. We will be considering the safety and efficacy of surfactant use - this will include timing of administration and administration techniques. |
| Chiesi Limited | 9 | 10 | Please define what 'respiratory support' is in this outcome. The duration of mechanical ventilation is associated with increased rates of bronchopulmonary dysplasia, but not with non-invasive respiratory ventilations modes such as CPAP/High flow/NiPPV. | Thank you for your comment. Duration of respiratory support has been removed as a surrogate outcome. We will be looking at different types of |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

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| | | | Please also consider the type of ventilator support required to maintain the infants (not just the duration). Evidence suggests that although infants may start on CPAP, the may subsequently need mechanical ventilation (CPAP failure – associated with higher risk of pneumothoraxes). | invasive and non-invasive ventilation in one of the review questions. |
| Chiesi Limited | 9 | 12 | Please consider using 'chronic lung disease' (CLD) which is a general term for long-term respiratory problems in premature babies and it includes BDP. If BDP is used, consider using CLD as well as BDP for the literature searches. | Thank you for your comment. We will develop detailed search protocols for each question to ensure we do not miss clinical evidence that is relevant. We have continued to use the term bronchopulmonary dysplasia as this is more specific to the preterm population which is now the focus of this scope. |
| Department of Health | General | General | I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation. | Thank you for your comment. |
| ENT UK | 5 | 25 | ENT are most commonly involved in children with intubation injuries and failed extubation. Techniques for management of endotracheal tubes e.g nasal intubation and avoiding cuffed tubes to prevent injury to the airway should be included. | Thank you for your comment. The details of endotracheal tube placement have not been prioritised for inclusion in this guideline. |
| Neonatal and Paediatric Pharmacists Group (NPPG) | General | General | We would recommend that a specialist neonatal pharmacist is included in the Guideline Development Group (GDG). We would be prepared to ask our members to consider applying for a position on the GDG. | Thank you for your comment. A specialist neonatal pharmacist position on the guideline committee was advertised. |
| Neonatal and Paediatric Pharmacists | 5 | 16 | We welcome that the consultation will consider medicines used in preventing and managing respiratory disorders on the neonatal unit. | Thank you for your comment. The scope includes a review of the safety and efficacy of a number of different medications. |

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| Group (NPPG) | | | | |
| Neonatal Critical Care Clinical Reference Group | 1 | 5 | Although the Department of Health and NHS England has asked NICE to produce a guideline on Specialist Neonatal Care, it is our opinion that the scope of such a project is far too broad. The title suggests a review of an entire subspecialty and we would question the rationale behind a project of such magnitude, which would be impossible to cover in a single guideline, particularly within the timeframe outlined.<br>The Neonatal Critical Care Clinical Reference Group (CRG) is currently reviewing neonatal care in England and the review findings will be of relevance to any guideline NICE intends to develop in this area. The review may identify areas where we think a new guideline is or would be of value. We would welcome direct discussion between NICE and the CRG as part of the review and guideline development. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on the respiratory support of preterm babies up to and including discharge planning. |
| Neonatal Critical Care Clinical Reference Group | 1 | 22 | The draft scope appears to be almost entirely focussed on respiratory disorders of babies requiring specialist neonatal care. It is unclear why this focus is required, given the key facts and figures stated in lines 10-21 (page1). In that regard the title Specialist Neonatal Care' is misleading. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Neonatal Critical Care Clinical Reference Group | 2 | 6 | Although, as stated, babies with bronchopulmonary dysplasia may need prolonged respiratory support, this group only make a small contribution to the increasing numbers of babies and children requiring long term and home ventilatory support. Provision of home ventilatory support is not within the remit of specialist neonatal care, although carefully planned transition from specialist neonatal care to long term ventilation services is clearly important. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

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| Neonatal Critical Care Clinical Reference Group | 2 | 9 | We welcome the focus on reducing variation in admission policies and clinical practice with regard to full-term admissions for specialist neonatal care and are engaged with NHS Improvement's Avoiding Term Admissions into Neonatal Units (ATAIN) programme of work. | Thank you for your comment. |
| Neonatal Critical Care Clinical Reference Group | 2 | 20 | We do not think that the Royal College of Paediatrics and Child Health currently endorse the 1998 Guidelines for good practice in the management of neonatal respiratory distress syndrome from the British Association of Perinatal Medicine, as these guidelines are considerably out of date and no longer operational. There are other, more recently publications widely used by neonatologists in England to inform local guidelines. In particular the recently updated European Consensus Guidelines on Management of Respiratory Distress Syndrome – 2016 update, is widely regarded for this purpose. | Thank you for your comment. We have removed the cross-reference to the 1998 guideline and included the European Consensus Guidelines for Respiratory Distress Syndrome instead. |
| Neonatal Critical Care Clinical Reference Group | 2 | 23 | If the focus of this guideline is on respiratory care, then the British Committee for Standards in Haematology guideline on transfusion for fetuses, neonates and older children is not specific to this and has minimal useful reference in this regard. | Thank you for your comment. We have removed the reference to this guideline on transfusion. |
| Neonatal Critical Care Clinical Reference Group | 2 | 25 | The 2016 Care Quality Commission's (CQC) review on Identifying and managing clinical risk in newborn babies and providing care for infants in the community who need respiratory support is of little relevance to a guideline on Specialist Neonatal Care. The CQC review is based on a single case, albeit with important lessons to be learnt for specialist neonatal care as well as for specialist paediatric and community services. It is focussed on the diagnosis and management of hypertension, which is an extremely rare condition in neonates, and the provision of care for infants in the community who need respiratory support. Although many babies who require community respiratory support transition from neonatal services, their management is provided outside of | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |

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## Stakeholder comments table

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|---|---|---|---|---|
| | | | specialist neonatal care and therefore a NICE guideline on management of this group of patients should be titled differently in order to reflect this. | |
| Neonatal Critical Care Clinical Reference Group | 3 | 4 | The term 'tertiary centres' should be replaced by Neonatal Intensive Care Units (NICUs), as this is the currently accepted terminology with respect to neonatal unit designation. | Thank you for your comment. This terminology has been changed as requested. |
| Neonatal Critical Care Clinical Reference Group | 4 | 16- | As previously stated, a guideline on specialist neonatal care should not restrict key areas covered to respiratory care only. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Neonatal Critical Care Clinical Reference Group | 4 | 4 | As previously stated, it is unclear why a guideline titled Specialist Neonatal Care has such a strong focus on infants requiring respiratory support. Such a focus would only be appropriate for a guideline on respiratory support in specialist neonatal care. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Neonatal Critical Care Clinical Reference Group | 4 | 6 | It is also unclear why the focus on respiratory support has such a strong emphasis on home care for chronic lung disease, as this represents a very small component of specialist neonatal care. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other |

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| | | | | comments, to focus on respiratory support of preterm babies up to and including discharge planning, but not detailed guidance on home care. |
| Neonatal Critical Care Clinical Reference Group | 5 | 2 | If the guideline is to focus on respiratory problems of the newborn, then management of persistent pulmonary hypertension of the newborn should not be excluded as this is a common cause of respiratory failure in term neonates | Thank you for your comment. Pulmonary hypertension has not been prioritised for inclusion as it mainly occurs in term babies. |
| Neonatal Critical Care Clinical Reference Group | 5 | 6 | The term 'hyaline membrane disease' is a pathological entity diagnosed at post-mortem examination and should be replaced by surfactant deficiency lung disease, which is the correct clinical term. | Thank you for your comment. We have removed this term from the scope. |
| Neonatal Critical Care Clinical Reference Group | 5 | 24 | It is inappropriate to exclude problems in all other body systems from a guideline titled Specialist Neonatal Care. Of particular note is the prevention and treatment of infection, nutritional management of babies with respiratory disease and neurodevelopmental follow-up and outcome. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. Other NICE guidelines covering other aspects of neonatal care will be cross-referenced where appropriate. |
| Neonatal Critical Care Clinical | 6 | 15 | It should be noted that the NICE guideline on Intravenous fluid therapy in children and young people in hospital (NG29) does not provide recommendations for babies born prematurely whose corrected age is less than term. | Thank you for your comment. We have removed reference to this guideline. |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

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| Reference Group | | | | |
| Neonatal Critical Care Clinical Reference Group | 6 | 19 | It should be noted that the NICE guideline on Gastro-oesophageal reflux in children and young people: diagnosis and management (NG1) does not specifically provide recommendations for babies born prematurely whose corrected age is less than term. | Thank you for your comment. The population covered by this guideline includes babies born preterm so we have left this cross-reference. |
| Neonatal Critical Care Clinical Reference Group | 7 | 9 | As previously stated, a guideline titled Specialist Neonatal Care should address a much wider range of key issues and questions than those related to the respiratory system. | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Neonatal Critical Care Clinical Reference Group | 7 | 19 | See comment 12 above. | Thank you for your comment. Please see the response to comment 12. |
| Neonatal Critical Care Clinical Reference Group | 10 | 3 | It should be noted that the NICE guideline titled Endovascular closure of patent ductus arteriosus refers to a minimally invasive procedure normally carried out in late infancy and does not form part of regular specialist neonatal care. | Thank you for your comment. We will be including patent ductus arteriosus only in terms of the impact of closure on preventing or alleviating bronchopulmonary dysplasia. |
| NHS England | **General** | General | We can confirm that there are no comments to be made on behalf of NHS England. | Thank you for your comment. |

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## Stakeholder comments table

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| Oxford University Hospitals | 3 | 10 | This should also be relevant to children's community nurses, Hospices, and general paediatricians and GPs | Thank you for your comment. We consider these to be covered under 'healthcare professionals in primary, secondary and tertiary care'. We have not included hospices as palliative or end of life care as this has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. |
| Oxford University Hospitals | 4 | 4 | Infants who need respiratory support in the neonatal period may die (in some cases as a result of a planned palliative extubation). This would require input from staff with palliative care experience | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 4 | 6 | Infants who have very significant CLD may need long term ventilation and thus benefit from palliative care services | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |

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| Oxford University Hospitals | 4 | 13 | Also the 3rd sector? (specific neonatal charities as well as hospices and respite providers) | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 5 | 1 | Infants on long term ventilation often benefit from stepped discharge / transitional care provided by children's hospices | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 5 | 19 | Full information should include details of palliative options as well as other treatments, where appropriate | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |

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## Stakeholder comments table

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| Oxford University Hospitals | 5 | 21 | Discharge planning for any infants felt to be life limited or life threatened could include children's hospice services | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 6 | 2 | Resuscitation should include adequate advance care planning, and thus include the decision making around resuscitation | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 6 | 5 | Related guidelines should include NG 61 End of Life Care for infants, children & young People (Dec 2016) | Thank you for your comment. We have included this in the related guidelines section. |
| Oxford University Hospitals | 7 | 12 | Does this include consideration of when NOT to intubate / resuscitate? Should allow for these decisions to made in the context of antenatal advance care planning. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and |

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| | | | | young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. As the focus of this guideline is on preterm babies, antenatal planning will not be included. |
| Oxford University Hospitals | 8 | 16+ | Support should include that available from palliative care teams (where appropriate) and should consider the needs of siblings and grandparents (as well as parents). | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. This includes consideration of the wider family. |
| Oxford University Hospitals | 9 | 1 | Discharge planning for those on long term ventilation should involve palliative care teams, hospices and community nursing teams, where appropriate. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |

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## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Oxford University Hospitals | 9 | 18 | 'Quality of death' should be examined for those who die | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Oxford University Hospitals | 9 | 19 | Parents and carer experiences should include siblings and grandparents | Thank you for your comment. We have used the term parents/carers in this scope but recognise that carers can include grandparents and other relatives. |
| Oxford University Hospitals | 9 | 19 | Families of babies who have died should be interviewed about their experiences too (easily forgotten if contact is lost following bereavement). | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline, and includes support for families after bereavement. |
| Royal College of Nursing | General | General | The Royal College of Nursing welcomes the opportunity to review and comment on the draft scope of this guideline. | Thank you for your comment. |

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## Consultation on draft scope
## Stakeholder comments table

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| Royal College of Nursing | 9, 10/12 | 4 | Yes there are NICE guidance that will require updating when the evidence for this is gathered. | Thank you for your comment. NICE guidance is reviewed in a planned way and updated to ensure published guidance is current. |
| Royal College of Nursing | 2/12 | 14-17 | This is the most important reason for NICE to produce not just this guideline but several others as there is tremendous variations in the way so many conditions are managed. Even within a regional network, hospitals do different things with regards to full ventilation, continuous positive airway pressure (CPAP), line management, Total parenteral nutrition (TPN), gut priming etc. The use of corticosteroids to prevent and manage bronchopulmonary dysplasia (BPD) is one such example.<br><br>When referring to BPD should the term Chronic Lung Disease (CLD) not also be used as a term as it is more parent friendly? Parents and not some nurses may not be finely attuned to the subtlety of this medical definition. | Thank you for your comment. We agree that the aim of this guidance is to promote best practice and evidence-based care. We have retained the terminology bronchopulmonary dysplasia as this is more specific, and relevant now the scope focusses on preterm babies. |
| Royal College of Nursing | 7/12 | | Section 3.5 - All this is very welcome and much needed however concerns could be expressed that the acute management of the infant needing ventilation and respiratory support is then combined with the chronic condition and then ongoing management with discharge.<br><br>A view could be expressed that these are 3 very different areas, if each is done comprehensively this guideline could be absolutely massive. If produced separately the discharge guideline in particular could have transferable elements and be used in other complex infant discharges and get infants out of the Neonatal Unit (NNU) into the community. | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Royal College of Nursing | 8/12 | | 3.5 sub section 4 - Parents seem to be included as a bolt on - they should be integrated into each section of the guideline. For example the needs of the shell shocked and traumatised parents of a very preterm infant fully ventilated are very different to the needs of an infant stable on CPAP and could be out for cuddles and Kangaroo care. | Thank you for your comment. We have included a new question on the involvement of parents, carers and other family members in the care of |

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# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
|---|---|---|---|---|
| | | | The support and management of the frustration of the CLD/BPD infants parents' needs careful and sensitive consideration and the requirements of the parents of the infant being discharged would be another potentially very detailed section.<br><br>These are stepped information stages - one size will not suit all. | babies receiving respiratory support. We will address the need for 'stepped information stages'. |
| Royal College of Nursing | 8/12 | | 3.5 sub section 5 - This is likely to include management of the tracheostomy and home oxygen. Guidance in this will be very welcome as management is currently very variable. There are pockets of excellence in some areas in other areas there are families who fear to sleep. | Thank you for your comment. Tracheostomy management has not been prioritised for inclusion in this guideline. The guideline will include discharge planning for babies who have had respiratory support in hospital (beginning in the neonatal period) and who need continued support for chronic lung disease. |
| Royal College of Nursing | 9/12 | 3.6 | Many of these could be guidelines of their own. There is some overlap but Necrotising Enterocolitis (NEC) for example is idiopathic and not always associated with respiratory support, CLD/BPD and could in some circumstances exist in isolation and require its own complex discharge package. Cerebral Palsy also could be an antenatal or intranatal event and not associated with the core groups that this guideline focuses on.<br><br>Equally so developmental delay, quality of life and family experience are not fixed points that can be measured as outcomes. What timeframe / snapshot is going to be used as it could be stated that there is no clear census point. | Thank you for your comments. These are the key outcomes that will be used to determine the effectiveness of interventions and will be further defined when the protocols are developed for each review question. |
| Royal College of Nursing | 1, 12 | 24-27 | Each of these could be a guideline on its own. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other |

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| | | | | comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Royal College of Nursing | 1, 12 | 6 | There are many guidelines which could be produced to support neonatal care. This proposed scope has a very restricted focus. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Royal College of Nursing | 4, 12 | 4-5 | This would include the pre-term as well as the baby born at term -lines 9 and 10 of the draft scope noted but if specifically stated at this point lines 9 and 10 would not be needed. Clarification that there are subtle differences in management between 'term' and 'pre term'. | Thank you for your comment. The scope has now been amended to include respiratory support only in preterm babies. |
| Royal College of Nursing | 11, 12 | | Algorithm - This looks odd, putting pedantic aside, the discharge looks like it is facilitated before the early management, the diagnosis and the ongoing management. | Thank you for your comment. The algorithm has been revised in light of stakeholder comments, and will be reviewed further during the development of the guideline |
| Royal College of Paediatrics and Child Health | General | General | Our reviewer feels that the title of the guideline is incorrect and misleading. They suggest that perhaps it should be called 'Specialist neonatal respiratory care'. This is a reasonable focus to have a guideline about, but if it excludes such a massive amount of specialist neonatal care e.g. cardiac, gastrointestinal, nutritional, renal, surgical etc., then the title must be more specific. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Royal College of Paediatrics and Child Health | General | General | It would be very useful if the group were to provide guidance on management of severe hypoxaemia and PPHN covering preterm and term infants given the numerous drugs used with varying levels of evidence e.g. sildenafil, magnesium sulphate, NO (preterms), tolazoline (preterms). This condition represents a small cohort of babies but they are challenging to manage and I suspect associated with high mortality. | Thank you for your comment. As the scope now only includes babies born preterm, severe hypoxaemia and persistent pulmonary hypertension of the newborn (PPHN) have not been prioritised for inclusion as they are mainly seen in term babies. |
| Royal College of Paediatrics and Child Health | Section 1 | | Current Practice –<br>This states that "Respiratory support is used in different ways in different units, and it is unclear<br>what the best method is". There is however good evidence that CPAP ideally from the delivery room, prevents lung injury, and European Consensus Guidance recommends CPAP for infants < 30 weeks with early rescue surfactant (European Consensus Guidelines on the Management of Respiratory Distress Syndrome – Sweet et al Neonatology 2016;111(2):107-125 | Thank you for your comment. The scope includes a review of respiratory support methods (including continuous positive airway pressure [CPAP]) before arrival in the neonatal unit. We have now included a reference to the European Consensus Guidelines on the Management of Respiratory Distress Syndrome in the scope. |
| Royal College of Paediatrics and Child Health | 3.3 | 3.3 | The scope should specify that it will look at oxygen therapy guidance for chronic lung disease as well as for acute respiratory management. This will affect the definitions of chronic lung disease in 3.6 (Outcomes) too. | Thank you for your comment. The guideline scope will include respiratory support (including oxygen therapy) for babies born preterm up to discharge from hospital to home, and will include discharge planning for babies who have had respiratory support in hospital (beginning in the neonatal period) and who need continued support for chronic lung disease. |
| Royal College of | Section 3.3 | 5 | Our reviewer agrees that there is a need to address guidance for babies that need long term invasive and non-invasive ventilatory support: pathways of care and importantly | Thank you for your comment. The scope covers respiratory support for |

## Consultation on draft scope
## Stakeholder comments table

### [Thursday 12/01/17 to 09/02/17]

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|---|---|---|---|---|
| Paediatrics and Child Health | | | ideal time frames for going home. They see increasing numbers of these babies in their Tertiary Units. Currently although they are commissioned only for care for 4 weeks post term, many of these children are on their neonatal units for considerably longer due to lack of HDU/PICU facilities. Furthermore, according to the Lond on Long Term Ventilation team, it can take a year for these children to go home | babies born preterm but commissioning issues relating to length of stay or transfer between units have not been prioritised for inclusion. |
| Royal College of Paediatrics and Child Health | Section 3.6 | | Main outcomes - Should also include length of time on oxygen | Thank you for your comment. We have to limit the number of outcomes we use and have selected those which we think are most important. These will be reviewed when we develop the protocols for each question. |
| Royal College of Paediatrics and Child Health | 3.6 | 3.6 | The reviewer suggest other outcomes that could be looked at would include long term respiratory outcomes e.g. respiratory morbidity at 2 years, re-admission to hospital with respiratory infections e.g. RSV, duration of oxygen therapy in BPD. | Thank you for your comment. We have to limit the number of outcomes we use and have selected those which we think are most important. These will be reviewed when we develop the protocols for each question. |
| Royal College of Paediatrics and Child Health | 3.3; 3.5 | | Respiratory disorders should include pulmonary haemorrhage and ventilator-associated pneumonia (VAP). The scope could include the definition, prevention and management of VAP, which is under-recognised in neonates, in part because there is no agreed definition. | Thank you for your comment. Pulmonary haemorrhage and ventilator-associated pneumonia are complications of ventilation and so will be included in the consideration of the effectiveness and safety of different assisted ventilation techniques. |
| Staffordshire, Shropshire & Black Country | General | General | 1. Which interventions or forms of practice might result in cost saving recommendations if included in the guideline? | Thank you for your comment. We will be identifying which particular review questions require a health economic analysis to identify cost savings or |

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## Consultation on draft scope
## Stakeholder comments table

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|---|---|---|---|---|
| Newborn and Maternity Network | | | Early airway/respiratory management with CPAP / Hi flo and appropriate use of surfactant may reduce length of ventilation and overall length of stay resulting in a cost saving<br><br>Appropriate fixing of ET tubes reduce unplanned extubations reducing known associated morbidities resulting in cost savings through reduction in length of stay and reduced number of consumables used<br><br>Guidance on routes of medicines specifically Caffeine IV vs Oral as IV caffeine is more expensive so cost saving if guidance identifies when babies can move from IV to oral earlier | increased costs. The details of endotracheal tube fixing have not been prioritised for inclusion in this guideline. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 1 | 4 | The title of the guideline should be changed to Specialist Neonatal Respiratory care **if** only care associated with Respiratory Disorders is going to be covered in this NICE guideline – **however** if the scope of this guideline is widened to include other important aspects of neonatal care see comment 3 below, then the current title will be fine. | Thank you for your comment. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 3 | 4 | The term 'tertiary centres' should be avoided and the currently accepted unit designation terminology Neonatal Intensive Care Unit (NICU) should be used. | Thank you for your comment. We have made this change to the terminology used in the scope. |

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## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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|---|---|---|---|---|
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 4 | 16 | Need to add Sedation/ Paralysis / Pain Assessment and Management as a Key area that will be covered in the guideline | Thank you for your comment. We have added a review question to address this within the scope. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | General | The detection and management of hypotension has a bearing on ventilation and therefore needs to be included in the scope of the guideline | Thank you for your comment. We have added a review question to address blood pressure monitoring within the scope. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | General | The prevention and management of morbidity associated with neonatal respiratory care needs to be covered in the scope of this guideline. E.g. Oxygen targeting in relation to ROP | Thank you for your comment. We have added a review question that will specifically look at oxygen targeting and retinopathy of prematurity (ROP) will be one of the outcome measures. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | General | Invasive and non-invasive monitoring of babies during respiratory care needs to be included in the scope of this guideline | Thank you for your comment. We have added review questions that specifically look at monitoring to allow appropriate adjustment of respiratory support. |

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## Consultation on draft scope
## Stakeholder comments table

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| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | General | Guidance on the amount of respiratory care days that need to be undertaken within neonatal units to optimise outcomes for babies needs to be included in the scope of this guideline | Thank you for your comment. We don't think it is possible to define the number of days required to optimise outcomes as each case will be different. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 6 | The term Hyaline membrane disease should be replaced with Surfactant deficient respiratory distress syndrome | Thank you for your comment. We have removed this term from the scope. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 12 | Antenatal factors associated with preventing respiratory disorders such as the timing of delivery and the use of antenatal steroids should be covered in this guideline | Thank you for your comments. The guideline will cover focus on the respiratory support of preterm babies, starting in the neonatal period and will not therefore include antenatal factors such as the timing of delivery or use of antenatal steroids. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 24 | Need to state congenital abnormalities such as diaphragmatic hernia and CCAM are not covered in this guideline | Thank you for your comments. We have added congenital abnormalities to the list of areas that will not be covered. |

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## Consultation on draft scope
## Stakeholder comments table

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|---|---|---|---|---|
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 25 | Technical aspects of fixing Endotracheal tubes should be included in the scope of this guideline to assist in the stability in transfer of baby from delivery suite into the neonatal unit and reduce unplanned extubations which are known to be associated with an increase in morbidity | Thank you for your comment. The fixing of endotracheal tubes was not prioritised for inclusion in this guideline |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 26 | Managing persistent pulmonary hypertension of the newborn should be included in the scope of this guideline because this is interwoven with respiratory care | Thank you for your comment. As this scope now refers to babies born preterm, pulmonary hypertension has not been prioritised for inclusion as it mainly occurs in term babies. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 5 | 27 | Neonatal Feeding and Nutrition is an extremely important area of specialist neonatal care which affects the majority of babies accessing specialist neonatal care with known impact on outcomes in relation to head growth, Retinopathy of Prematurity and Necrotising Enterocolitis . We feel this aspect of care should be included in the NICE Specialist Neonatal Care Guideline. | Thank you for your comment. The specific management of nutritional support was not prioritised, We will log this issue for reconsideration at the next surveillance point. Parenteral nutrition is being covered in another NICE guideline which is currently in development. |
| Staffordshire, Shropshire & Black Country Newborn and | 7 | 15 | A sub question to 1 is:<br>1.2 how is respiratory support best maintained in the transit period after resuscitation, transferring baby from delivery suite to the neonatal unit? | Thank you for your comment. This question will focus on the respiratory support provided before and during transfer to the neonatal unit. |

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## Consultation on draft scope
## Stakeholder comments table

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| Maternity Network | | | | |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 7 | 17 | A sub question to 2 is:<br>2.3 what common general conditions manifest with respiratory distress in the newborn period (including PPHN, Sepsis, hypothermia etc) | Thank you for your comment. The scope has been revised to include only respiratory support for babies born preterm so the list of conditions to be considered has also been amended. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 7 | 28 | A sub question to 3 is:<br>What measures should be taken to prevent worsening of respiratory conditions in the newborn (e.g. use of CPAP in delivery room) | Thank you for your comment. This will be covered under question 1 - respiratory support before transfer to the neonatal unit. |
| Staffordshire, Shropshire & Black Country Newborn and Maternity Network | 8 | 16 | A sub question to question 4 is:<br>What information and in what format should be offered to parents and carers of infants who had a respiratory problem in the neonatal period that improves before discharge (e.g advice about long term sequelae of respiratory conditions) | Thank you for your comment. We will be reviewing what information is of most value to parents and carers, to identify if this should include advice about long-term sequelae. |
| Staffordshire, Shropshire & Black Country Newborn and | 9 | 6 | Growth and later cognitive outcomes should also be considered when searching for and assessing the evidence for this guideline. | Thank you for your comment. We have to limit the number of outcomes we use and have selected those which we think are most important. These will be |

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## Stakeholder comments table

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| Maternity Network | | | | reviewed when we develop the protocols for each question. |
| The Neonatal Society (committee) | General | | We recommend an additional key area that:<br>1. Lists outcomes that are amenable to quantitative evaluation of the guideline.<br>2. Includes a strategy for developing the regulatory and IT infrastructure needed to support efficient collection of research quality data for primary research and health service evaluation. | Thank you for your comments. With the exception of parent and carer experience, the majority of the outcomes listed are likely to be amenable to quantitative evaluation. The guideline committee will be making research recommendations in areas where there is a lack of evidence. Defining a strategy for regulatory and IT infrastructure to collect research data has not been prioritised for inclusion in this guideline. |
| The Neonatal Society (committee) | General | | We recommend a clear statement of the knowledge gaps and uncertainties that remain after appraising the evidence in the key areas, concluding with future directions for research. | Thank you for your comments. The guideline committee will discuss gaps and uncertainties and may make research recommendations in areas being covered, where there is a lack of evidence. |
| The Neonatal Society (committee) | General | | Provide the essential components of an education package to support implementation of the guidance. | Thank you for your comments. An education and implementation plan accompanies the release of all NICE guidelines |
| The Neonatal | 8 | 13 | Q3.8 assumes that closing a patent ductus arteriosus is desirable. We would prefer to see this question replaced with: | Thank you for your comment. We will be including patent ductus arteriosus (PDA) only in terms of the impact of |

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| Society (committee) | | | 1. What are the best metrics for predicting clinically significant effects of patent ductus arteriosus, and when should echocardiographic assessment of the PDA be considered in preterm infants?<br>2. When should closure of PDA be offered?<br>3. What is the evidence of efficacy and safety of interventions designed to close the PDA? | closure on preventing or alleviating bronchopulmonary dysplasia. Other aspects of PDA management suggested here were not prioritised for inclusion |
| The Neonatal Society (committee) | 8 | 31 | Immunisation of infants with chronic lung disease should be considered because of variations in the use of RSV vaccination. | Thank you for your comment. Immunisation and respiratory syncytial virus (RSV) vaccination were not prioritised for inclusion in this guideline. |
| The Royal College of Midwives (RCM) | General | | The RCM welcomes the development of this guideline, in the context of the identified variation of practice in neonatal units. | Thank you for your comment. |
| The Royal College of Midwives (RCM) | 2 | | Clear guidance on reasons for admissions of full term babies would be expected to be a cost saving. | Thank you for your comment. The scope will now only address babies born preterm. |
| The Royal College of Midwives (RCM) | 5 | | We agree with the key areas to be covered as outlined in the scope and are particularly pleased to see the inclusion of an evidence review of the diagnosis of meconium aspiration syndrome. | Thank you for your comment. |
| The Royal College of Midwives (RCM) | 8 | | We agree with the key issues and questions highlighted and welcome the focus on the support and information that should be offered to parents and carers. The lack of appropriate information giving has been an issue of concern for many years. | Thank you for your comment. |
| Together for Short Lives | General | General | When considering resuscitation, advance care planning is vital. An advance care plan (ACP) is agreed in advance between professionals and families if possible, and is | Thank you for your comment. The details of palliative care services and |

# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

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| | | | based on families' needs and wishes. Writing this plan can help to eliminate some of the family's anxieties, aid them in creating positive memories around the death of the child and make sure that their wishes and priorities are respected. Advance care planning with parents should begin during pregnancy if there is an antenatal diagnosis of a life-limiting condition. | their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. As the focus of this guideline is on preterm babies, antenatal planning has not been included. |
| Together for Short Lives | 3 | 11 | This will be relevant to voluntary palliative care organisations including children's hospices, children's community nursing teams and universal services provided by GPs, paediatricians and health visitors. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 3 | 13 | Change to 'parents and carers of babies admitted onto the neonatal unit', as 'children' cannot be admitted to neonatal units. | Thank you for your comment. We have now used the term babies throughout this scope. |
| Together for Short Lives | 4 | 13-14 | End sentence at neonates, or change 'neonates' to babies to be more accessible to parents using this document, as children are not admitted onto neonatal units. | Thank you for your comment. We have now used the term babies throughout this scope. |
| Together for Short Lives | 4 | 4 | Some of the babies within the scope of this guideline will die as neonates; their palliative care may be planned using the principles of the Together for Short Lives Extubation Pathway and the Together for Short Lives Neonatal/Perinatal Pathway. | Thank you for your comment. The details of planning for end of life, palliative care services and their involvement has recently been covered |

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## Consultation on draft scope
## Stakeholder comments table

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| | | | http://www.togetherforshortlives.org.uk/assets/0000/1059/Extubation_Care_Pathway.pdf<br>http://www.togetherforshortlives.org.uk/assets/0000/7095/Neonatal_Pathway_for_Babies_5.pdf | in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 4 | 13 | The list of settings should include voluntary sector palliative care organisations including children's hospices and baby hospice organisations. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 5 | 19 | Some of these babies will die as neonates; professionals' communications with their parents and carers should follow the principles set out in the Together for Short Lives Neonatal/Perinatal Pathway (see comment 2 for link). Their care should include parallel planning, which means also planning for end of life care while taking account of the often unpredictable course of life-limiting conditions. It involves making multiple plans for care and using the one that best fits the baby's circumstances at the time. Parallel planning can help a family to achieve the best quality of life and best quality of death possible for their baby. Families will also need to be offered end of life care and bereavement care. | Thank you for your comment. The details of planning for end of life , palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 5 | 21 | Discharge planning must take into account the infant being discharged to a location which may not be the family home. This may be a children's hospice, for example. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and |

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# [Specialist neonatal respiratory care for babies born preterm]

## Consultation on draft scope
## Stakeholder comments table

## [Thursday 12/01/17 to 09/02/17]

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| Stakeholder | Page no. | Line no. | Comments<br>Please insert each new comment in a new row | Developer's response<br>Please respond to each comment |
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| | | | | young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 6 | 5 | This section should include NG 61 End of Life Care for infants, children & young People (Dec 2016). This describes the care and support that babies, children and young people with life-limiting conditions - and their families - should expect to receive from the point at which their needs are recognised until the end of their lives. | Thank you for your comment. We have included this in the related guidelines section. |
| Together for Short Lives | 7 | 12 | This should include planning for not intubating and not resuscitating. This should be included where possible in the anticipatory care planning process. Professionals may suggest to families that it may not be in their baby's best interest to be resuscitated; however, the precise details about what the family want and do not want should be fully explored and documented in an anticipatory care plan as stated by NICE NG 61 End of Life Care for infants, children & young People (Dec 2016).<br><br>A written personal resuscitation plan should form part of an anticipatory care plan and be developed with the family, their consultant and other care team members. These plans allow families, in partnership with their health team, to tailor what interventions are appropriate for their baby. They will also assist communication between different professionals. If such a plan is not in place and there is no 'do not resuscitate' order in place, NICE guidelines NG 61 End of Life Care for infants, children & young People (Dec 2016) are to attempt to resuscitate the baby emphasising the importance of the anticipatory planning process to reflect appropriate interventions for the baby.<br><br>The Royal College of Paediatrics and Child Health has published 'Making Decisions to Limit Treatment in Life-Limiting and Life-Threatening Conditions in Children: A Framework for Practice' (RCPCH 2015) at http://adc.bmj.com/content/100/Suppl_2/s1.full | Thank you for your comment. The details of planning for end of life decisions such as this has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |

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|---|---|---|---|---|
| | | | Practical guidance for the management of palliative care on neonatal units, published by Chelsea and Westminster Neonatal Team and endorsed by The British Association for Perinatal Medicine (2014) also provides supportive information about difficult decision making. This is available to access at: http://www.bapm.org/publications/documents/guidelines/NICU-Palliative-Care-Feb-2014.pdf<br><br>It can be useful when there is disagreement within the team or family to seek an Ethics review by the local ethics group. This can be a very useful way in resolving some of the issues. | |
| Together for Short Lives | 8 | 16 | The needs of siblings, grandparents and other family members is crucial too. This support can be planned using the principles of the Together for Short Lives Neonatal/Perinatal Pathway (see comment 2 for link) and may need to start as early as the 20-week scan if this is when there is a diagnosis or recognition that the baby has a life-threatening or a life-limiting condition. | Thank you for your comment. We have used the term parents or carers in the scope but recognise that other family members must be included too. As this guideline focuses on preterm babies, antenatal support has not been included. |
| Together for Short Lives | 8 | 28 | 'and children' should be deleted from this line as babies are discharged from neonatal services, not children. | Thank you for your comment, this has been amended to 'babies' as suggested. |
| Together for Short Lives | 8 | 31 | For many parents, the knowledge that their baby needs palliative care, combined with their new status as potential parents, may lead to them making a choice to be discharged somewhere other than their own home. This may be a children's hospice, a relative's home or even their local hospital. If the baby is going to stay in hospital, a palliative care approach is still appropriate in parallel to their ongoing care. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. |

[Specialist neonatal respiratory care for babies born preterm]

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| | | | Discharge planning should therefore involve professionals from palliative care teams, hospices and community nursing teams. | This will be cross-referenced from this guideline. |
| Together for Short Lives | 9 | 18 | A good quality of death is an extremely important outcome and should be planned for in parallel to planning for quality of life. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 9 | 18 | Siblings, grandparents and other relatives/carers, where appropriate, should be included in discussions about choices regarding quality of life. | Thank you for your comment. We have used the term parents/carers in this scope but recognise that carers can include grandparents and other relatives. |
| Together for Short Lives | 9 | 18 | A family should be able to express a choice about where their child receives care; the location in which the care is provided should reflect both the family's preference and the what can realistically be offered locally. It is also important to remember that families may change their mind about a preferred location of care, in response to changing circumstances, and that plans may therefore need to be made in parallel. This is a time of continuing uncertainty and many parents feel overwhelmed with the many decisions and choices they are asked to make. Ongoing conversations providing the opportunity to talk are essential. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 9 | 19 | Families of babies who have died should be interviewed about their experiences too and followed up if accessing them via a bereavement service. | Thank you for your comment. The details of palliative care services and their involvement has recently been |

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| | | | | covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| Together for Short Lives | 11 | | Perinatal palliative and end of life care and death of the baby should be reflected in pathway. | Thank you for your comment. The details of palliative care services and their involvement has recently been covered in NICE clinical guideline 61 - End of life care for infants, children and young people with life-limiting conditions: planning and management. This will be cross-referenced from this guideline. |
| University College Hospitals London (UCLH) | General<br><br><br><br><br><br><br><br>9 | General<br><br><br><br><br><br><br><br>11,15,16, 17,18,19 | This draft guideline on specialist neonatal care principally relates to infants with respiratory disorders with the rationale given that 'respiratory disorders are among the most common problems in babies that need specialist neonatal care'. The focus of the document is on those infants who require respiratory support both in the neonatal unit and on discharge.<br><br>In spite of being included as main outcomes to be considered, there is little recognition that these outcomes are not influenced solely by the infant's respiratory disorder, alone.<br><br>Frequent co-morbidities occur in infants with chronic lung disease, particularly those with the need for long term respiratory support. These issues, such as the challenge of digesting comfortably, impact upon the baby's respiratory status and need to be considered along with the medical management included in the draft guideline. | Thank you for your comments. The title of the guideline has been revised to reflect the fact that it focuses on respiratory care. The scope has also been revised in light of this, and other comments, to focus on respiratory support of preterm babies up to and including discharge planning. We understand that other co-morbidities occur but in order to achieve adequate focus on this guideline the guideline committee will only consider evidence relating to respiratory management. |

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| | | | Developmental issues do not relate solely to the infant's respiratory status. During the time that respiratory support is given, specialist knowledge and input is required from therapists to support both the infant and their family in aspects such as bonding, positioning, development ( including feeding), social interaction. Medical, nursing and pharmaceutical management is included in the guideline but there is no consideration of the wider management of these infants requiring respiratory support during the neonatal period and on follow-up post discharge. The involvement of specialist developmental therapists:<br>1. supports the infant's development (reduces health, educational, social cost)<br>2. has the potential to help infant wean from respiratory support ( reduce length of stay)<br>3. Improves parent- infant relationship (promotes well-being, reduces parental anxiety and depression, positively influences developmental outcomes)<br><br>The above points were raised repeatedly by multi-professional agencies during the workshop held in December. I would ask that the committee reconsider their configuration to include specialist therapeutic representation. | We recognise the importance of specialist developmental therapists, and have included an extra review question on how best to involve parents in the care of their babies, and will be advertising for such a therapist to join the guideline committee. |

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