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# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## NICE guidelines

### Equality impact assessment

## Specialist neonatal respiratory care for babies born preterm

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

### 1.0 Checking for updates and scope: before scope consultation (to be completed by the Developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they?

The following groups were identified and discussed when drafting the guideline scope:

- Parents and carers of babies whose first language is not English

There were not thought to be potential equality issues with respect to the care provided to babies.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

It was agreed by the scoping group that recommendations by the Committee relating to support, information and communication should take into account parents and

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carers in whom English was not their first language.

**Completed by Developer:** Paul Jacklin - Guideline Lead

**Date:** 16/12/2016

**Approved by NICE quality assurance lead:** Sharon Summers-Ma

**Date:** 29/12/2016

### **2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)**

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

One stakeholder suggested that ethnically appropriate gestation cut-offs for intervention should be defined, in light of evidence of increased risk of adverse outcomes including meconium aspiration syndrome in women of south Asian and African origin.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

No, as interventions relating to the mother are not included in the scope.

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2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, do the key messages for the public need to be produced in an alternative version?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss
- British Sign Language videos for a population deaf from birth
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

Does an alternative version(s) of the consultation documents also need to be produced?

No.

**Updated by Developer:** Hilary Eadon

**Date:** 23/02/2017

**Approved by NICE quality assurance lead:** Sharon Summers-Ma

**Date:** 13/03/2017

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### 3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Yes, in the recommendations on providing information, it is stated that the information should be provided in the format preferred by the parent, and appropriate to their needs and preferences, and this would include different languages. In addition the information recommendations are cross-referenced to the NICE guideline on patient experience in adult NHS services which provides further advice on providing information (although this is a neonatal guideline this was felt to be applicable as it is the adults (parents/carers) who are receiving the information).

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Parents/carers who were unable (financially, logistically or for other reasons) to spend extended periods of time on the neonatal unit may miss out on the participation in their baby's care, becoming competent to care for their baby, and therefore may not be able to take their baby home as early as other parents. The committee discussed this and agreed that parents should be encouraged to visit as often as was possible, but agreed that it was outside the remit of the guideline to make recommendations on this issue.

Parents/carers who live in unsuitable accommodation may not be able to take their baby home as early as other parents. The committee addressed this by making the recommendation that discharge could be to a relative's house or other suitable accommodation.

The committee were concerned that some parents, such as those who were blind, deaf or had learning disabilities may not be able to take their baby home on respiratory support as they would not be able to operate the equipment or hear alarms. These parents may need additional support on discharge and the committee addressed this by making recommendations on early referral with the community and continuing healthcare teams so that this support could be put in place.

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3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

The considerations have been described in the 'Other considerations' section of committee's discussion of the evidence for the evidence reviews relating to questions 6.1, 6.2, 6.3, 7.1 and 7.2.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, there are no recommendations that are going to make it more difficult for certain groups to access care.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No, the recommendations will not have an adverse impact on people with disabilities.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

The committee took into consideration the barriers identified in question 3.2 as follows:

6.1 The committee considered the fact that some families found it difficult to be present on the neonatal unit every day or for long periods of time, and for these parents and carers these recommendations might be more difficult to implement, but the committee agreed that parents/carers should be encouraged to be present on the neonatal unit with their baby for as long as possible and as often as possible, depending on their individual circumstances.

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3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

6.2 The committee agreed that support should be provided in an accessible format – for example in different languages. Parents with low-literacy may struggle to participate in interventions that involve reading or writing their baby's notes or accessing other written information. The committee discussed the use of parent-buddies, particularly those that speak the same first language as the parents.

6.3 The committee agreed that information should be available in different languages and that print materials should be easily readable and accessible to parents with lower levels of literacy.

7.1 and 7.2 The committee discussed inequalities in access to social housing and service provision and the financial strains that having a preterm baby may place on parents/carers. Families who are ineligible for travel subsidies may find it difficult to regularly travel to the NICU before their baby is discharged, which could affect their ability to gain hands-on experience in daily care needs but the committee agreed that families should be encouraged to visit as much as possible. Additionally, families who are in unsuitable accommodation, or who cannot afford or obtain financial help to make adaptations to their homes may be unable to accommodate medical equipment or be able to provide a safe environment for their preterm baby, and the committee made recommendations that in such cases the baby could be discharged to other suitable accommodation such as a relative's home. The committee also took into account the need for the culturally sensitive delivery of information, as it was noted that different cultural groups may have different family structures and housing arrangements.

**Completed by Developer:** Hilary Eadon

**Date:** 06/08/2018

**Approved by NICE quality assurance lead:** Simon Ellis

**Date:** 08/10/2018

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### 4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

There was only one potential equality issue raised during consultation:

'What about translational services for parents who first language is not English and making reasonable adjustments for parents with a learning disability? Book without words may be a useful tool.'

The section on providing information (recommendations 1.6.9 to 1.6.13) already states that the information should be '...appropriate to the parents' and carers' needs and preferences' and this would include the options suggested (translated materials, adjustments for parents with learning disabilities). There is also already a cross-reference to the NICE guideline on patient experience in adult NHS services which provide further guidance on appropriate communication and information.

The committee did not therefore consider it was necessary to make any further changes to the recommendations to address this issue.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, there are no changes to the recommendations that make it more difficult in practice for a specific group to access services compared with other groups.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No, there are no changes to the recommendations that are likely to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

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4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.1, 4.2 and 4.3, or otherwise fulfil NICE's obligations to advance equality?

This is not necessary as the changes to the recommendations have not created and barriers or difficulties.

4.5 Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where?

The considerations of equality issues are, as prior to consultation, included in the committee's discussion of the evidence for questions 6.1, 6.2, 6.3, 7.1 and 7.2.

**Updated by Developer:** Hilary Eadon

**Date:** 18/12/2018

**Approved by NICE quality assurance lead:** Simon Ellis

**Date:** 22/01/2019