

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines Equality impact assessment

Developmental follow-up of children and young people born preterm

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

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

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

The following potential equality issues were identified during the scoping process and discussed with the Committee. The outcome is detailed below each:

- Individuals from multi-lingual backgrounds.
 - The Committee discussed the needs of children and families or carers who may not have English as a first language. They recognised that this potential issue affects aspects of the guideline, including communication, information and shared decision-making, as well as surveillance tools used at the 2 and 4-year enhanced surveillance assessments (for example, PARCA-R which is only available in English language). Evidence for differences in efficacy due to ethnicity and language characteristics was sought.
- Ethnicity (suggested that this might influence developmental norms).
 - The Committee discussed how recommendations should be kept sufficiently broad to allow a degree of clinical judgement for the individual child. Evidence on differences due to ethnicity was sought and reported where found.
- Individuals with a family history of learning difficulties or developmental problems and disorders.
 - The guideline recommends that readers refer to the principles outlined in the Patient Experience guideline, which requires “factors such as physical or learning disabilities be addressed so that they are able to participate as fully as possible”. In this case, this would typically involve asking the parent or carer if someone was available to accompany them during discussions.

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

- Travellers/people living in temporary accommodation.
 - The guideline recommends that enhanced developmental support be tailored to take account of individual preferences and needs.
- People from disadvantaged socio-economic groups.
 - The recommendations are not believed to discriminate against people from disadvantaged backgrounds and specifically mention this as a risk factor for developmental problems and disorders where evidence was available.
- Young maternal age (as this may impact on uptake of pre-term follow-up services).
 - The recommendations are not believed to discriminate against children with young mothers and specifically mention this as a risk factor for developmental problems and disorders where evidence was available.

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?

The Committee recommends that “level of education, social care needs, and cultural, spiritual or religious beliefs” be taken into consideration when providing information to parents or carers of preterm babies.

3.3 Were the Committee’s considerations of equality issues described in the consultation document, and, if so, where?

- Individuals from multi-lingual backgrounds.
 - Recommendation 1.2.3 “Follow the principles in the NICE guidance on patient experience in the NHS services in relation to communication (including different formats and languages), information and shared decision-making.” This is also discussed in relation to the recommended screening tools and diagnostic tests used at the 2 and 4-year enhanced surveillance assessments (for example, PARCA-R which is only available in English language), and flexibility has been incorporated for use of a “suitable alternative”, depending on the individual needs of the child. This was included in the protocols in appendix D and is discussed in the respective LETR sections of the

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

guideline (see section 5.1.1).

- Ethnicity (suggested that this might influence developmental norms).
 - The recommendations were kept broad to allow a degree of clinical judgement for the individual child. Evidence on differences due to ethnicity was sought and is reported when found, for example, recommendation 1.1.19, section 4 of the full guideline. This was also included in the protocols in appendix D.
- Individuals with a family history of learning difficulties* or developmental problems and disorders.
 - The guideline recommends that readers refer to the principles outlined in the Patient Experience guideline, which requires “factors such as physical or learning disabilities be addressed so that they are able to participate as fully as possible”, recommendation 1.2.3, section 5.1.1 of the full guideline. This was also included in the protocols in appendix D.
- Travellers/people living in temporary accommodation.
 - The guideline recommends that enhanced developmental support be tailored to take account of individual preferences and needs, recommendation 1.3.4, section 5.1.4 of the guideline. This was also included in the protocols in appendix D.
- People from disadvantaged socio-economic groups.
 - The recommendations are not believed to discriminate against people from disadvantaged backgrounds and specifically mention this as a risk factor for developmental problems and disorders where evidence was available, for example recommendation 1.1.12, section 4 of the guideline
- Young maternal age
 - The recommendations are not believed to discriminate against people of a young maternal age and specifically mention this as a risk factor for developmental problems and disorders where evidence was available, for example recommendation 1.1.12, section 4 of the guideline
- Education, social care needs, and cultural, spiritual or religious beliefs, for example recommendation 1.2.2 as discussed in section 5.1.1 of the full guideline

*Note: the term 'intellectual disability' is being discussed by the NICE Equalities Group meeting on 2nd March, and any changes to the terminology will be reflected in future guidance.

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?

The recommendations for enhanced surveillance require additional assessments at the age of 2 and 4 years for some children. Those born in a regional unit (that is, rural communities) may experience transport and cost issues associated with these requirements.

Increased levels of contact and engagement with services, as required by the recommendations, for certain children who are born preterm will require additional use of interpreters for children and their parents or carers who do not speak English.

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.

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 possibility of conducting the 2 and 4 year assessments by telephone interview was considered by the Committee. For the 2-year assessment, the PARCA-R can be administered over the phone along with general developmental enquiry. Parents and carers can be asked if they have concern about hearing and motor development and their feedback can be used to determine whether the child needs to be seen in person. However, this is not ideal. Because of the nature of the 4 year assessment this should be delivered in person.

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