NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality and health inequalities assessment (EHIA) template

Sickle cell disease: managing acute painful episodes in hospital (NG143)

The considerations and potential impact on equality and health inequalities have been considered throughout the guidance development, maintenance and update process according to the principles of the NICE equality policy and those outlined in <u>Developing NICE guidelines: the manual</u>.

Appendix B: equality and health inequalities assessment (EHIA)

Sickle cell disease: managing acute painful episodes in hospital (NG143)

STAGE 1. Surveillance review

Date of surveillance review: June 2023.

Focus of surveillance review: How should an acute painful sickle cell episode be managed using pharmacological interventions?

CfG Exceptional review

1.1 On reviewing the existing EIA or EHIA and issues log for the guideline(s), describe below any equality and health inequalities issues relevant to the current surveillance review.

Scoping (2011): developers reported that no equality issues were identified but consideration would be given to people who are pregnant (safety considerations) and children (as they follow a different pathway to adults).

Guideline development (2012): Developers noted that access and provision of treatment for an acute painful sickle cell episode is not limited to particular groups. Therefore, recommendations are phrased to promote equality. Recommendation 1.1.10 highlights the need to consider pregnant women differently when offering regular paracetamol and NSAIDs.

Recommendations note that patients should be cared for in an age-appropriate setting and dosages (in which case healthcare professionals should refer to the BNF for information) and the use of age-appropriate pain scoring tools for assessing pain.

1.2 Did you identify any equality and health inequalities issues through initial intelligence gathering (for example, national policy documents, topic expert/patient group feedback, evidence searches, implementation data)?

Sickle cell disease (SCD), one of the most common inherited disorders, is associated with vaso-occlusive pain episodes and haemolysis leading to recurrent morbidity, hospital admissions and work or school absenteeism.

It is estimated that there are between 12,500 and 15,000 people with SCD in the UK. The prevalence of the disease is increasing because of immigration into the UK and new births. SCD mainly affects people of African or African-Caribbean origin, however, the sickle gene is found in all ethnic groups. It also commonly affects people of Mediterranean and Middle Eastern origin.

The management of acute painful sickle cell episodes for people presenting at hospital is variable throughout the UK, and is a frequent source of complaints.

Sickle Cell Health Awareness, Perspectives and Experiences (<u>SHAPE</u>) international survey (including UK) identified that more than a third (38%) of patients said they believed their ethnicity was a factor in receiving poor healthcare. More than half felt they received poor care because healthcare professionals lacked knowledge about the condition.

An UK All Party Parliamentary Group (APPG) enquiry into avoidable deaths and failures of care for sickle cell patients in secondary care, <u>No one's listening (2021)</u>, made findings under the following headings:

- Sub-standard care on general wards and in A&E
- Failings in providing joined-up sickle cell care
- Low awareness of sickle cell among healthcare professionals and inadequate training
- Negative attitudes towards sickle cell patients
- Inadequate investment in sickle cell care

The report also acknowledges that there is routine failure to comply with national care standards or NICE standards around pain relief when patients attend A&E.

1.3 If you have consulted stakeholders or topic experts, what questions did you ask about equality and health inequalities issues?

Not applicable – no consultation or expert engagement.

1.4 What equality and health inequalities issues have been identified during this surveillance review and what was the impact on the current review and outcome decision?

Access barriers to effective care is a major factor driving health inequalities for people with SCD. The APPG reported that emergency departments and general wards are not delivering the level of care recommended by the NICE guideline CG143.

The APPG report highlights issues that stem from some healthcare staff not having the knowledge and experience to follow the CG143 recommendations and this, along with resource constraints and inadequate training, would appear to be the main barrier to successfully implementing the recommendations. As the barriers to implementation relate directly to staff knowledge and experience, there are no direct issues with the NICE guideline or quality standard.

The APPG report also identifies the role of racism in the negative attitudes towards sickle cell patients, which overwhelmingly affects people with African or Caribbean heritage.

The APPG report calls on NICE to revise CG143 guideline around pain relief for sickle cell patients to set out standards relating to pain management in the entirety of a sickle cell crisis, not just delivery of the first dose. However, the guideline does cover the time beyond first dose. The current 2023 review was an opportunity to establish if there is new evidence to update recommendations.

The APPG report also highlights a distinct lack of investment in sickle cell research and treatments. The current review sought to identify ongoing research within the scope of the guideline surveillance review.

No update is planned following the NICE 2023 surveillance check, largely due to limited new evidence.

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