NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE QUALITY STANDARDS

Quality standard topic: Sickle cell acute painful episode

Output: Equality analysis form – Meeting 2

Introduction

As outlined in the Quality Standards process guide (available from www.nice.org.uk), NICE has a duty to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations between people from different groups. The purpose of this form is to document the consideration of equality issues in each stage of the development process before reaching the final output that will be approved by the NICE Guidance Executive. This equality analysis is designed to support compliance with NICE's obligations under the Equality Act 2010 and Human Rights Act 1998.

Table 1 lists the equality characteristics and other equality factors NICE needs to consider, i.e. not just population groups sharing the 'protected characteristics' defined in the Equality Act but also those affected by health inequalities associated with socioeconomic factors or other forms of disadvantage. The table does not attempt to provide further interpretation of the protected characteristics. This is because it is likely to be simpler, and more efficient, to use the evidence underpinning the quality standard to define population groups within the broad protected characteristic categories rather than to start with possibly unsuitable checklists created for other purposes, such as social surveys or HR monitoring tools.

The form should be used to:

- confirm that equality issues have been considered and identify any relevant to the topic
- ensure that the quality standards outputs do not discriminate against any of the equality groups
- highlight planned action relevant to equality
- highlight areas where quality standards may advance equality of opportunity.

This form is completed by the NICE quality standards internal team at each stage within the development process:

- Topic overview (to elicit additional comments as part of active stakeholder engagement)
- Quality Standards Advisory Committee meeting 1
- Quality Standards Advisory Committee meeting 2

Table 1

Protected characteristics
Age
Disability
Gender reassignment
Pregnancy and maternity
Race
Religion or belief
Sex
Sexual orientation
Other characteristics
Socio-economic status
Depending on policy or other context, this may cover factors such as social exclusion and deprivation associated with geographical areas or inequalities or variations associated with other geographical distinctions (e.g. the North/South divide, urban versus rural).
Marital status (including civil partnership)

Other categories

Other groups in the population experience poor health because of circumstances often affected by, but going beyond, sharing a protected characteristic or socioeconomic status. Whether such groups are identifiable depends on the guidance topic and the evidence. The following are examples of groups covered in NICE guidance:

- Refugees and asylum seekers
- Migrant workers
- Looked after children
- Homeless people.

Quality standards equality analysis

Stage: Meeting 2

Topic: Sickle cell acute painful episode

1. Have any equality issues impacting upon equality groups been identified during this stage of the development process?

 Please state briefly any relevant equality issues identified and the plans to tackle them during development.

At the topic overview stage it was identified that most people affected with sickle cell disease are of African or African-Caribbean origin, although the sickle gene is found in all ethnic groups. The prevalence of the disease is increasing because of immigration into the UK and new births. Statements 1 and 2 recognise the possible language barriers this may present when using pain scoring tools.

The topic overview stage also recognised that the distribution of the disease reflects the multi-ethnic population in the UK. About two thirds of people with sickle cell disease live in London, with the majority of others in major urban areas such as the West Midlands and Manchester. To account for these differences in service needs across the country, statement 5 has been developed on access to local protocols and specialist support so regardless of where someone presents in the country they can receive high quality care.

At the final stage of development, following consultation, it was recognised that sickle cell disease is a rare condition with a wide geographical variation in prevalence, lack of awareness of the disease and its symptoms have been shown to cause deaths, and potential risks are associated both with the high chance of reoccurrence and the use of strong analgesia. A statement was therefore developed on the provision of discharge information to ensure the person with the acute painful sickle cell episode knew how to access services and further support if needed.

No further equality issues have been identified at this stage.

2. Have relevant bodies and stakeholders been consulted, including those with a specific interest in equalities?

 Have comments highlighting potential for discrimination or advancing equality been considered?

Standing members for Quality Standards Advisory Committees (QSACs) have been recruited by open advert with relevant bodies and stakeholders given the opportunity to apply. In addition to these standing committee members, specialist committee members from a range of professional and lay backgrounds relevant to sickle cell acute painful episode were recruited.

The first stage of the process gained comments from stakeholders on the key quality improvement areas which were considered by the QSAC.

Consultation on the draft quality standard took place with registered stakeholders for a period of 4 weeks. All comments received were considered by the QSAC and a high level summary report produced of those consultation comments that may result in changes to the quality standard (see NICE website).

- 3. Have any population groups, treatments or settings been excluded from coverage by the quality standard at this stage in the process? Are these exclusions legal and justified?
 - Are the reasons for justifying any exclusion legitimate?

The quality standard will cover the management of sickle cell acute painful episode in people in hospital from the time of presenting to hospital until the time of discharge. It will not cover other aspects of the sickle cell pathway. The referred topic was sickle cell acute painful episode and this is the scope of the guideline.

- 4. If applicable, do any of the quality statements make it impossible or unreasonably difficult in practice for a specific group to access a service or element of a service?
 - Does access to a service or element of a service depend on membership of a specific group?
 - Does a service or element of the service discriminate unlawfully against a group?
 - Do people with disabilities find it impossible or unreasonably difficult to receive a service or element of a service?

Statements 1 and 2 both make reference to the use of an age-appropriate pain scoring tool that should take into account age, especially if the person is a young child, and any physical, sensory or learning disabilities. Most people with sickle cell disease are of African or African-Caribbean origin. This may mean that language needs to be taken into account when deciding on the type of pain scoring tool to be used.

In statement 1, one aspect of the assessment is to establish that the pain is due to a sickle cell acute painful episode and not because of another cause. In young children, those with cognitive difficulties or those in great pain it may not be possible to determine the cause of the pain initially without a fuller examination following receipt of the initial analgesia.

Statement 6 highlights that all discharge information given to people with an acute painful sickle cell episode should be culturally appropriate and accessible to people with additional needs, such as physical, sensory and learning disabilities, and to people who do not speak or read English. They should also have access to an interpreter. The statement also highlights that it may be appropriate in some cases, particularly with children and young people, to provide information to parents and carers as well as the person with the acute painful sickle cell episode.

5. If applicable, does the quality standard advance equality?

 Please state if the quality standard, including statements, measures and indicators, as described will advance equality of opportunity, for example by making access more likely for certain groups, by tailoring the service to certain groups, or by making reasonable adjustments for people with disabilities?

We believe these statements promote equality.