NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARDS

Quality standard topic: Familial hypercholesterolaemia

Output: Equality analysis form – Topic Expert Group three

Introduction

As outlined in the Quality Standards Programme interim 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 Expert Group meeting one - Scoping
- Topic Expert Group meeting two – creation of draft quality standard
- Topic Expert Group meeting three – creation of final quality standard.

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: Topic Expert Group three

Topic: Familial hypercholesterolaemia

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.

Several equality groups were identified as being relevant for this quality standard.

- Ethnic groups – there has been little research into the prevalence of familial hypercholesterolaemia between ethnic groups. The national audit of the management of familial hypercholesterolaemia 2010 reported the ethnicity of the cases reviewed and found 75% of adults and 58% of children were white British. It is not known if this is representative of people with familial hypercholesterolaemia as a large proportion of the population is unknown.
- Children, particularly very young children, may have difficulties accessing appropriate testing and treatment based on their age.

The quality standard will be inclusive and ensure statements are relevant for all groups. Where there may be a particular issue for children specific statements may be developed.

Two statements have been developed specifically on ensuring early diagnosis and management in children to address the issue of access. The statements specify the diagnostic tests and initiation of treatment should be offered by the age of 10 if the child is at risk due to one affected parent.

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?

To gain multiple perspectives from all stages of familial hypercholesterolaemia, representation within the Topic Expert Group was sought from a variety of audiences including consultant physicians, general practice, specialist nursing, commissioning, lay members, academics and genetic counseling.

Consultation on the draft quality standard took place with registered stakeholders for a period of 4 weeks. All comments received were considered by the developers and the TEG and have been responded to on a line by line basis (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 not cover people with secondary hyperlipidaemia and other inherited lipid disorders. It will also not cover people with homozygous FH because this is a small population requiring specialist services.

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?

The statements do not prevent any specific group from accessing services.

The TEG noted quality statement 1 has been restricted to adults only because the criteria stated for assessment of a clinical diagnosis of FH is not appropriate for children. Quality statement 6 has also been restricted to adults only because there is currently no evidence on which to base any specific target for lowering LDL-C in children. However, lipid-modifying drug treatment should be considered by the age of 10 years in line with NICE clinical guideline 71. Quality statement 6 also highlights that women with FH should be advised that lipid-modifying drug treatment should not be taken if they are planning to conceive or during pregnancy because of the potential risk of fetal abnormality. Women who are pregnant should be advised on the potential risks and benefits of re-starting therapy if breast feeding.

Quality statements 4 and 7 have been developed specifically on diagnosis and management in children to address the issue of access in younger children.

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 quality statements promote equality.

Quality statement 7 highlights that all children, both boys and girls, should have equal access to lipid-modifying drug treatment for FH. Gender should not influence a clinician's decision to offer treatment; the decision should be made in accordance with the recommendations in NICE clinical guideline 71, which indicate that lipid-lowering with statins should be considered by the age of 10 years.