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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

CG71- Familial hypercholesterolaemia

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

1.0 Scope: before 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 development of the draft scope, before consultation, and, if so, what are they?
n/a- CGUT does not have a scoping phase
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?
n/a- CGUT does not have a scoping phase

Completed by Developer: Susan Spiers
Date 9th May 2017

Approved by NICE quality assurance lead: Nichole Taske
Date 16th October 2017

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2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?
n/a- CGUT does not have a scoping phase
2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?
n/a- CGUT does not have a scoping phase

<p>2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?</p> <p>If so, is an alternative version of the 'Information for the Public' document recommended?</p> <p>If so, which alternative version is recommended?</p> <p>The alternative versions available are:</p> <ul style="list-style-type: none">• large font or audio versions for a population with sight loss;• British Sign Language videos for a population who are deaf from birth;• 'Easy read' versions for people with learning disabilities or cognitive impairment.
No

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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?

n/a- CGUT does not have a scoping phase

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?

During the development meetings the committee discussed various potential equality issues, these are:

- Consideration was given to patients where English is not their first language, and there may be the need for translation services during consultations and cascade testing. To make recommendations on this is beyond the scope of the update, but is a core principle of the NHS constitution.
- If either indirect or direct cascade testing is used, then written materials would need to be available in alternative formats/ languages. Translation services would need to be considered if contacting people by phone call. To make recommendations on this is beyond the scope of the update, but is a core principle of the NHS constitution.
- There may be issues with contacting affected relatives in families who are estranged, including single parent families and in cases of adoption. There may also be inequalities in contacting relatives where indirect cascade testing is used. It is beyond the scope of the update to make recommendations on this, but commissioning groups should take this into account when implementing services.
- There is regional variation in availability of and access to FH services and testing; this may affect the detection of FH in relatives who live in different regions of the UK. Therefore, people at risk of FH who are unidentified and untreated (relatives of an individual with FH) are at higher risk of a cardiovascular event than an at risk person who has been identified and treated. It is beyond the scope of the update to make recommendations on this, but commissioning groups should take this into account when implementing services.
- Ethnicity: in general there is a lack of data on prevalence of FH in different ethnic groups: it has been suggested that FH is less common in people of African family origin. This lack of information on prevalence of FH in people from different ethnic groups could adversely affect case finding due to lack of knowledge. This has been addressed by new research recommendations which include an outcome of establishing the prevalence of FH in people of different family origin.

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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?

- Gender: males with FH have a risk of MI at an earlier age than females, this reflects the general population. However, in both males and females with FH, there is a greater risk of MI in untreated FH. To make recommendations on this is beyond the scope of the update.
- Young people: there may be a greater risk of MI in younger people with FH if they remain untreated, Effective early treatment reduces their risk to that of the general population. Therefore identification of FH and appropriate treatment from an early age is required to reduce risk of cardiovascular events. This has been addressed by the new recommendation 'Offer statins to children with FH by the age of 10 years or at the earliest opportunity thereafter' which emphasises prompt treatment of children with FH to reduce the risk of MI to that of the general population.
- Pregnancy/ breastfeeding: the recommended first line treatment for FH is a high-intensity statin. Pregnant or breastfeeding women are advised not to take statins. Therefore women of childbearing age should have access to appropriate advice and counselling with regards to other treatments that may be more appropriate if at any time they are unable to take statins. It is beyond the scope of the update to address this issue. There are existing recommendations within the FH guideline which cover this issue (see "information for pregnant women with FH").

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

These are outlined in the "other considerations" section of the linking evidence to recommendations section 2.6, 3.6 and 4.6.

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?

Compared to people of European family origin, genetic testing may not be as acceptable by people from people of black, Asian and minority ethnic groups. Experience from other genetic screening programmes such as for thalassaemia, indicate that specific outreach programmes are needed for black, Asian and minority ethnic groups to ensure a high acceptance rate. Similarly, cascade testing may meet with specific barriers in certain groups of people, for example where arranged marriage occurs and a genetic disease may be seen as an impediment.

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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?

Where a person does not speak English, language difficulties may need to be addressed by preparation of translated information materials.

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?

None identified.

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?

All recommendations made during the update should alleviate barriers or difficulties with access to services. The committee discussed how difficulties could be overcome (e.g. letters available in alternative formats or languages) in the "other considerations" section of linking evidence to recommendation sections 2.6, 3.6 and 4.6.

There is not a specific recommendation, but as discussed above, specific outreach programmes may be needed for certain ethnic groups to ensure a high acceptance rate of genetic testing and cascade testing. Where a patient is not a native English speaker, language difficulties may need to be addressed by preparation of translated information materials.

Completed by Developer: Susan Spiers

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Approved by NICE quality assurance lead: Nichole Taske

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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?

At consultation, stakeholders raised that having a single total cholesterol threshold for case finding may not be optimal, and raises equality issues around both age (younger people have lower cholesterol on average) and sex (cholesterol distributions in men and women vary differently by age).

The committee discussed the appropriate number of age categories by which to nuance the case finding threshold. It was felt that splitting the population into a larger number of groups would provide more granularity and ensure that the recommendations addressed variation in cholesterol levels across age groups more accurately. However, the committee also agreed that case finding on a primary care database is a time-consuming activity, and introducing a large number of age groups would substantially increase the workload for GP surgery staff, making the recommendations less likely to be implemented. Furthermore, in the absence of an audit tool for FH case finding, practice staff would have to design and conduct their own searches, which could act as a further barrier to implementation.

The committee agreed that specifying thresholds for two age groups (patients aged 16-29 and patients aged >30) struck an appropriate balance between these two competing factors. These groupings appropriately account for the lower total cholesterol levels in younger patients, while retaining a practical number of groups for case finding on a practice system.

The committee also discussed the potential for nuancing the threshold by sex. It was noted that if the preferred age groups of 16-29 and >30 were further subdivided by sex, the resulting total cholesterol thresholds would be lower for males than for females across both groups. The committee agreed that such a divide would favour males, as the thresholds do not adequately reflect the period between the ages of 25-55 where, on average, males have a higher total cholesterol than women. It was felt that, to appropriately reflect the intersectionality between age and sex, at least 4 age brackets would be required, resulting in 8 subgroups overall. The committee considered that, on balance, a simpler recommendation with only 2 thresholds based on age would likely result in better guidance uptake and adherence, and would therefore provide greater benefit to both sexes than a more nuanced recommendation which is impractical to implement. Moreover, the committee noted that the variation in total cholesterol according to patients' age is substantially greater than according to gender, and therefore nuancing recommendations by the former axis is of primary importance.

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

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?

After consultation, the recommendation on case finding was amended so that rather specifying a single threshold for total cholesterol, two different thresholds were specified, based on age. The reasons for and effects of this are discussed in section 4.1 above.

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 relevant issues were identified.

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 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

Nothing additional to what is discussed in section 4.1 above.

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

These issues are discussed in the evidence to recommendations sections associated with each review.

Completed by Developer: Sue Spiers
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