NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Familial breast cancer

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?
Not applicable (Clinical Guideline Updates do not include 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?
1) Those with intellectual disabilities: assessing the mental state/capacity of an individual with intellectual disabilities can be a complex process due to the difficulties associated with determining medical history. Understanding a woman's development and learning disability will therefore affect the assessment and what conclusions can be drawn from it. In light of this, the Committee thought that for those with intellectual disabilities, appropriate assistance such as interpreters/carers should be present when needed to make decision making easier for the individual. Those with intellectual disabilities were thought less likely to seek advice when needed and should hence be encouraged by family members/carers to attend clinics, etc. 2) Pregnancy: the Committee questioned the safety of chemopreventative drugs during pregnancy and noted that it is not advisable to take these

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drugs during pregnancy or when trying to conceive. An existing recommendation from the original guideline (1.7.29) informs women that they should stop tamoxifen at least 2 months before trying to conceive. 3) English not first language: individuals who do not speak English as a first language may not be able to fully describe their medical history in English. Consequently the committee highlighted it may be difficult to accurately establish clinical characteristics and symptom history which could lead to misclassification. This also has implications for discussing and understanding the different treatment options and benefits and harm associated with them. Interpreters where possible should hence be available to assist. 4) Age: Although the inclusion criteria of chemoprevention trials included in the evidence review restricted entry to women aged roughly 30 years and older, the committee agreed not to set a minimum age limit for accessing chemopreventive drugs. The committee did not want to restrict young women from having access to preventative treatment as there may be some who wish to discuss options other than risk reducing surgery. In addition, young age does not reduce the effectiveness of these treatments. Therefore for women of all ages, a full and detailed discussion about the risks and benefits of chemoprevention should be carried out. 5) Written information: The committee noted that providing appropriate written and verbal information on risks and benefits would give women the opportunity to make an informed choice. The committee agreed this could be assisted by a patient decision aid to include specific examples of these risks and benefits. The recommendations also include some specific examples of risks to assist in these discussions, including the need to discuss alternative approaches to chemoprevention such as risk reducing surgery. Facilities to assist those with low literacy/first language not English should be available throughout the process. 6) Religion/culture – the committee noted that in some religions and cultures, cancer is not openly talked about which prevents family members from seeking further help early on. 7) Sex/gender reassignment: the committee noted that although the evidence related specifically to women, breast cancer can also affect men however is much rarer in this group. The committee also discussed gender

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reassignment as an equality issue given the role chemopreventative drugs could play in reversing gender reassignment for men taking female hormones. 8) Refugees and asylum seekers: the committee also noted that these groups may have limited knowledge of their family history. No.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?
Yes - these are contained in the 'other considerations' section of the Linking Evidence To Recommendations table in the guideline. Relevant subgroups have also been specified in the review protocol.

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?
No

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?
English not first language. Services should ensure that clinicians have access to interpreters when engaging with individuals who do not speak English as a first language.

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