

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DIAGNOSTICS ASSESSMENT PROGRAMME

Equality impact assessment – Scoping

Testing strategies for Lynch syndrome in people with endometrial cancer

The impact on equality has been assessed during this assessment according to the principles of the NICE Equality scheme.

1. Have any potential equality issues been identified during the scoping process (scoping workshop discussion, assessment subgroup discussion), and, if so, what are they?

All people with cancer are covered under the disability provision of the Equality Act (2010) from the point of diagnosis. Information from tests in this assessment may influence decisions on fertility and conception. Pregnancy is a protected characteristic under the Equality Act.

The specificity of MSI and IHC to detect potential Lynch syndrome associated endometrial cancer may decrease in older cohorts because the occurrence of somatic *MLH1* promoter hypermethylation increases with age (that is, a larger proportion of endometrial tumours with deficient MMR will be because of somatic, rather than inherited, causes with increased age).

Clinical experts highlighted that endometrial cancer is often the first Lynch syndrome related cancer that occurs in women with the condition. Therefore, only testing for Lynch syndrome in people with colorectal cancer might disadvantage women more than men. Testing people at the point of endometrial cancer diagnosis will provide an opportunity to identify the condition earlier and prevent subsequent Lynch syndrome related cancer.

Clinical experts further commented that the numbers of variants of unknown significance that are identified may vary by ethnicity. People from ethnic groups in which few studies identifying mutations in Lynch syndrome associated genes have been done are more likely to have a variant of unknown significance identified by testing. This might be more of

an issue when a strategy of direct to germline testing is used because there will be no corresponding tumour test done to show likely effect of variant so variants of unknown significance may be more likely.

Accessing relevant medical records and tumour samples to decide if testing for Lynch syndrome is appropriate may be more difficult if the person was treated for a Lynch syndrome-related cancer outside of the UK.

2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

The potential equality issues will be noted by the Committee and inform discussions where appropriate.

3. Has any change to the draft scope been agreed to highlight potential equality issues?

The potential equality issues have been included in the equalities section of the scope.

Population subgroups have been added to the scope so evidence will be collected where available and used to inform Committee.

4. Have any additional stakeholders related to potential equality issues been identified during the scoping process, and, if so, have changes to the stakeholder list been made?

No.

Approved by Associate Director (name): Sarah Byron

Date: 25/07/2019