

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health Technology Evaluation

Equality impact assessment – Scoping

Sirolimus for treating facial angiofibroma from tuberous sclerosis complex in people 6 years and older [ID3990]

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

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

The following equalities issues were raised during the first round of scoping consultation and workshop (November 2022):

1. Previous dermatology appraisals noted that assessment tools for severity & response to treatment (specifically the Psoriasis Area and Severity Index (PASI) and Freckles Area and Severity Index (FASI)) may not be sensitive enough in people with darker skin pigmentation.
2. Previous dermatology appraisals also noted that physical, psychological, sensory or learning disabilities, or communication difficulties could affect responses to DLQI (Dermatology Life Quality Index). Other tuberous sclerosis complex topics also highlighted that a large proportion of people with the condition have neuropsychiatric disorders of varying severity.
3. At the scoping workshop it was highlighted that the DLQI may not be useful in younger children but can be useful in young people.

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

Issue 1 – severity and response assessment in people with darker skin.
Clinical experts at the scoping workshop explained that the angiofibroma

tends to be pigmented in darker skin, which makes it more visible. So, it is unlikely that a different assessment of severity or response will occur in people with darker skin pigmentation. Also, the FASI and PASI tools are validated but not systematically used in facial angiofibroma. However, the committee should ensure it considers whether the tools used within the company submission are suitable for all skin pigmentations.

Issue 2 – appropriateness of DLQI

The technical team suggests this issue is considered by committee during the appraisal.

Issue 3 – Age

Committee should consider whether the tools used are capable of measuring disease-specific quality of life in children.

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

None required.

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): Emily Crowe

Date: 14/12/23