

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY APPRAISAL PROGRAMME

### Equality impact assessment – Guidance development

### STA Risdiplam for treating spinal muscular atrophy in children and adults

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

#### Consultation

1. Have the potential equality issues identified during the scoping process been addressed by the committee, and, if so, how?

The scoping process raised issues around:

- equal access to treatments regardless of SMA type and age (this was restricted in the clinical evidence)
- considering that the SMA population includes people with disabilities
- considering that an oral treatment like risdiplam will be more accessible than treatment with nusinersen because it is administered intrathecally and requires patients and carers to travel to hospitals

The committee considered these points but agreed that these were not equality issues because the recommendation applies to all people with SMA within the marketing authorisation for risdiplam, regardless of age or disability.

2. Have any other potential equality issues been raised in the submissions, expert statements or academic report, and, if so, how has the committee addressed these?

The patient and professional submissions suggested that the use of arbitrary disease categories means some patients with SMA (adults and those with

type 3 SMA) cannot access treatments. The committee discussed this and recognised the limitations but noted that these classifications had been used in the marketing authorisation and the clinical evidence. A clinical expert commented that the evidence did not fully capture the diverse ethnic demographic seen in people with SMA. However, the committee noted that the recommendation applies to all people with SMA within the marketing authorisation for risdiplam, regardless of ethnicity.

3. Have any other potential equality issues been identified by the committee, and, if so, how has the committee addressed these?

No

4. Do the preliminary recommendations make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

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

6. Are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with, access identified in questions 4 or 5, or otherwise fulfil NICE's obligations to promote equality?

No

7. Have the committee's considerations of equality issues been described in the appraisal consultation document, and, if so, where?

Yes see section 3.20 in the appraisal consultation document

**Approved by Associate Director (name):** Ross Dent

**Date:** 20/05/2021

## Final appraisal determination

(when an ACD issued)

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the committee addressed these?

Web comments were received that noted the small population with SMA because it is a rare disease and that conditions that are more prevalent often have more treatment options and less unmet need.

The committee discussed the nature of SMA and acknowledged the difficulty of appraising drugs for very rare conditions. It took into account the rarity and severity of SMA in its decision-making (see section 3.25 of the appraisal consultation document)

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 the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

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

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 identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality?

No

5. Have the committee's considerations of equality issues been described in the final appraisal determination, and, if so, where?

Section 3.23 of the FAD

**Approved by Associate Director (name):** Ross Dent

**Date:** 06/10/2021