

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

Nusinersen and risdiplam for treating spinal muscular atrophy [ID6195]

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

Final draft guidance

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

During the scoping process, the following potential equality issues were raised:

- Nusinersen would be provided at a limited number of specialist centres, there is the potential for issues of equity of access based on geographic location.
- Recommending only one treatment for routine commissioning would not allow equitable access for the whole population in scope. Some people with SMA have scoliosis and cannot receive nusinersen, while others experience adverse side effects with risdiplam.

Access to specialist centres is an implementation issue; it is not an equality issue that can normally be addressed by a technology appraisal.

The committee considered that its recommendations for nusinersen and risdiplam do not make it more difficult in practice for a specific group to access treatment compared with other groups.

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?

Yes, the following potential equality issues were raised:

- The company submissions did not include evidence for people with SMA type 0 and type 4, potentially excluding them from treatment
- Excluding people who need long-term ventilation could raise equality concerns because they can be considered disabled. Also, NHS England noted challenges in assessing benefit for severely disabled people because fine motor skills are not well captured by current tools
- Treatment access affected by age because spinal access is needed for nusinersen but not risdiplam. This would disproportionately affect people aged about 25 years and over, because their historic spinal fusion surgeries did not preserve the intrathecal access route for nusinersen (because it wasn't yet available as a treatment option). NHS England also noted challenges in assessing benefit in children and young people because it is difficult to separate motor milestone gains from a person growing normally and the direct impacts of treatment

The committee noted that it had not seen clinical and cost-effectiveness evidence related to type 0 and type 4 SMA. But it concluded that the SMA 'type' classification system for SMA is somewhat arbitrary and is becoming outdated. And it heard from clinical experts that people with type 4 SMA may benefit from treatment. So, it decided not to exclude people with type 4 or type 0 SMA from its recommendation and concluded that decisions about potential to benefit from treatment should be made by clinical teams.

The committee concluded that its recommendations do not restrict access to treatment for some groups of people over others, so concerns around disability and age were not potential equality issues.

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

No other potential equality issues were identified by the committee.

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?
Not applicable

7. Have the committee's considerations of equality issues been described in the appraisal consultation document, and, if so, where?
Yes, sections 3.38 and 3.39 of the final draft guidance.

Approved by Associate Director (name): Ross Dent

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