

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health Technology Evaluation

### Equality impact assessment – Scoping

#### **Intrathecal onasemnogene abeparvovec for treating spinal muscular atrophy in people 2 years and over [ID6556]**

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?

At scoping consultation, stakeholders identified the following issues.

1. Not all neuromuscular centres are currently equipped to deliver and monitor intrathecal SMA treatments. Intrathecal delivery requires specialist anaesthesia and sometimes interventional radiology which may not be uniformly available across centres. There is a risk that patients may be unable to access treatment due to uneven distribution of facilities and clinical capacity across the UK. This could disproportionately affect those living in remote or underserved areas.
2. People with SMA often experience varying levels of disability. Requiring travel to distant infusion centres may pose a barrier to equitable access, particularly for those with limited mobility or support.
3. Socio-economic status may limit how often people can attend repeated appointments at specialist centres, which could worsen existing inequalities in access to care.
4. Young people with SMA moving from paediatric to adult care may face gaps in specialist support, leading to unequal continuity of care.
5. Standard outcome measures may not be accessible for children with bulbar impairment, so this subgroup may be under-represented in trial and registry data.

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

Committee will consider whether its recommendations could have a different impact on people protected by the equality legislation than on the wider population during the appraisal process.

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

No.

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?

Not applicable.

**Approved by Associate Director (name):** .....Lorna Dunning ...

**Date:** ...19<sup>th</sup> November 2025...