

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health Technology Evaluation

Equality impact assessment – Scoping

Tofersen for treating amyotrophic lateral sclerosis caused by SOD1 gene mutations [ID3767]

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?

Yes, the following potential equality issues were identified:

- Where a person lives may impact their ability to receive treatment promptly because to initiate treatment people need access to genetic testing and a safe and appropriately staffed neurology service able to deliver and monitoring intrathecal treatment.
- Tofersen cannot be delivered if the person having it cannot lie flat on their back so consideration must be given to people who can not lie flat on their back.

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

Access to genetic testing and treatment centres is an implementation issue that cannot be addressed by a technology appraisal.

The method of administration can not be addressed by a technology appraisal.

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?

Yes the Royal College of Radiologists has been added as a consultee.

Approved by Associate Director (name):Richard Diaz

Date: 30 March 2026