

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health Technology Evaluation

### Equality impact assessment – Scoping

#### **Doxecitine–doxribtimine for treating thymidine kinase 2 deficiency in people of any age [ID6484]**

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. Stakeholders noted that:

- Thymidine kinase 2 deficiency (TK2D) causes high levels of disability and profound quality of life and economic effects on the people with the disease, their carers and their families.
- Many children affected by TK2d have nursing mothers because the age of onset is frequently in the first two years of life.
- Doxecitine and doxribtimine new drug application has been accepted by the FDA and granted priority review. If approved, this would represent a geographical inequality in that people living with the same condition in the USA would gain access to a drug not available to patients in England.
- Many people who live with TK2D are full-time ventilator dependant and so require constant access to a functioning electricity supply. Families living in rural or remote areas of England, such as Devon and Cornwall, may therefore be more vulnerable to power outages, leaving them at greater risk of succumbing to this life-limiting disorder if unable to access a functioning electricity supply, whilst also living with greater levels of anxiety and uncertainty related to this.

- In practice, access to genetic testing and specialist centres may vary by region or socioeconomic status.
- Making this treatment available to only a subset of individuals would lead to substantial inequalities among the TK2D community.

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

Disability and pregnancy and maternity are protected characteristics under the Equality Act 2010.

Nursing mothers are likely to fall within the 'pregnancy and maternity' protected characteristics group. However, this issue raised relates to the carer burden associated with babies and young children diagnosed with this condition. The committee in its deliberations should consider carer burden and whether it is appropriate to include carer QALYs in the calculation of cost effectiveness.

Where appropriate, the committee will consider the impact the recommendation may have for people with protected characteristics and on the other equality issues raised.

The committee can only evaluate this topic within its marketing authorisation.

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?

No.

**Approved by Principal Technical Adviser (name):** Christian Griffiths

**Date:** 13/08/2025