NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date and time:** Thursday 10 June 2021, 9:00am - 14:15pm

**Location:** Zoom

## Attendees

Committee members present

1. Dr Paul Arundel (Chair) Present for all items
2. Dr Peter Jackson (Vice Chair) Present for all items
3. Professor Ron Akehurst Present for all items
4. Sotiris Antoniou Present for all items
5. Sarah Davis Present for all items
6. Carrie Gardner Present for all items
7. Dr Shehla Mohammed Present for all items
8. Dr Mark Sheehan Present for all items
9. Matt Smith Present for all items
10. Professor Lesley Stewart Present for all items
11. Karen Whitehead Present for all items
12. Karen Samuels Present for all items

NICE staff present

Nicole Elliott, Associate Director Present for all items

Jo Ekeledo, Project Manager Present for all items

Adam Brooke, Technical Advisor Present for all items

Sharlene Ting, Technical Analyst Present for all items

Gemma Smith, COT Coordinator Present for all items

Sophie McHugh, COT Administrator Present for all items

Lucinda Evans, Coordinator Present for items 1 to 3.2

Mandy Tonkinson, MIP Present for items 1 to 3.2

Ann Greenwood, Editor Present for all items

University of York representatives present

Mr Mark Simmonds, ERG, University of York Present for items 3.3

Mr Rob Hodgson, ERG, University of York Present for items 3.3

Experts present

Ayesha Ali, Commissioning Expert, NHSE Present for items 1 to 3.2

Mrs Nicola Elson, Patient Expert, ArchAngel Present for items 1 to 3.2

Prof Paul Gissen, Clinical Expert, Orchard Therapeutics Present for items 1 to 3.2

Dr Simon Jones, Clinical Expert, Orchard Therapeutics Present for items 1 to 3.2

Mrs Georgina Morton, Patient Expert,

Alex,The Leukodystrophy Charity Present for items 1 to 3.2

Mrs Sophie Thomas, Patient Expert,

Mucopolysaccharide Society Present for items 1 to 3.2

## Minutes

### Introduction to the meeting

* 1. The chair welcomed members of the committee and other attendees present to the meeting.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Thursday 13 May 2021

### Evaluation of OTL-200 for treating metachromatic leukodystrophy [ID1666]

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external group representatives, members of the public and company representatives from Orchard Therapeutics
     2. The chair asked all committee members, professional experts, external group representatives and NICE staff present to declare any relevant interests in relation to the item being considered.

* Lesley Stewart declared a Non-Financial Professional & Personal Interests interest as she is employed by the University of York and directs the work of the York TAR team who are the ERG for this evaluation. However, she has had no involvement whatsoever in the work.

It was agreed that her declaration would not prevent Lesley Stewart from providing expert advice to the committee

* Georgina Morton declared a Indirect financial interest as ArchAngel MLD Trust received a grant of £5000 in December 2019 from Orchard Therapeutics in support of work towards newborn screening for MLD and ArchAngel MLD Trust, The MPS Society and MLD Support Association UK have jointly received a grant of £11,600 in August 2020 to carry out an MLD patient and caregiver burden survey.

It was agreed that her declaration would not prevent Georgina Morton from providing expert advice to the committee.

* Sophie Thomas declared an Indirect personal Interest as she has been a patient advocate for MPS Society since 2002 and a PPV member of RDAG since March 2021.

t was agreed that her declaration would not prevent Sophie Thomas from providing expert advice to the committee.

* Simon Jones declared a Direct financial interest as he works with orchard in an ad hoc consulting capacity on MPSI, MPSIIIA and MLD. He is also an investigator in a clinical trial (in MPSIIIA) sponsored by the university of Manchester but funded by orchard.

It was agreed that his declaration would not prevent Simon Jones from providing expert advice to the committee.

* 1. Part 2a – Closed session (members of the public and professional experts were asked to leave the meeting. The company and evidence review group remained).
     1. The committee discussed confidential information submitted for this item.
  2. Part 2b – Closed session (company representatives and external group representatives were asked to leave the meeting)
     1. The committee then agreed on the content of the Evaluation Consultation Document (ECD). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Evaluation Consultation Document (ECD) in line with their decisions.

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 15 July and will start promptly at 09:00am.