NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Unconfirmed

**Date and time:** Wednesday 10 February 2021

**Location:** Zoom

# Committee members present

1. Peter Jackson (Chair) Present for all items
2. Paul Arundel (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. Stuart Davis Present for all items
7. Carrie Gardner Present for all items
8. Jeremy Manuel Present for all items
9. Dr Shehla Mohammed Present for all items
10. Dr Mark Sheehan Present for all items
11. Matt Smith Present for all items
12. Professor Lesley Stewart Present for all items
13. Karen Whitehead Present for all items

# NICE staff present:

Helen Knight, Programme Director Present for all items

Nicole Elliott, Associate Director Present for all items

Joanne Ekeledo, Project Manager Present for all items

Lucinda Evans, Coordinator (MIP) Present for items 1 to 3.3

Daniel Greenwood, COT Assistant Administrator Present for all items

Heidi Livingstone, Senior Public Involvement Adviser Present for items 1 to 3.3

Rosalee Mason, Coordinator (MIP) Present for items 1 to 3.3

Sophie McHugh, COT Administrator Present for all items

Alan Moore, Technical Lead Present for all items

# External group representatives present:

Samantha Barton, ERG Representative, BMJ Group Present for items 1 to 3.3

Tracey Jhita, ERG Representative, BMJ Group Present for items 1 to 3.3

# Professional experts present:

Ayesha Ali, Commissioning Expert, NHSE Present for items 1 to 3.3

Gennadiy Ilyashenko, Patient Expert, TreatSMA Present for items 1 to 3.3

Umut Izgi, Patient Expert, SMA UK Present for items 1 to 3.3

Fiona Marley, Commissioning Expert, NHSE Present for items 1 to 3.3

Adan Manzur, Clinical Expert, Novartis Gene Therapies Present for items 1 to 3.3

Liz Ryburn, Patient Expert, SMA UK Present for items 1 to 3.3

Volker Straub, Clinical Expert, Novartis Gene Therapies Present for items 1 to 3.3

Paul Weinberger, NHSE Commissioning Expert Present for items 1 to 3.3

# Observers present:

Helen Barnett, Editor, NICE Present for all items

Emily EatonTurner, HTA Adviser, NICE Present for all items

Alex Filby, Technical Adviser, NICE Present for all items

Philip Ranson, Comms Lead, NICE Present for all items

Abitha Senthinathan, Technical Adviser, NICE Present for all items

Indeg Sly, NHSE Present for all items

Thomas Strong, HTA Adviser, NICE Present for all items

## **Introduction to the meeting**

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

## **News and announcements**

* 1. None.

## **Evaluation of ID1473 Onasemnogene abeparvovec for treating spinal muscular atrophy**

* 1. Part 1 – Open session
     1. The chair welcomed the invited professional experts, external group representatives, members of the public and company representatives from Novartis gene therapies
     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.
* Volker Straub declared a Financial Interest as he received speaker honoraria from Sanofi Genzyme and has participated in advisory boards for Audentes Therapeutics, AveXis, Biogen, Bristol-Myer Squibb, Exonics Therapeutics, Italfarmaco S.p.A., Pfizer, Roche, Sanofi Genzyme, Sarepta Therapeutics, Summit Therapeutics, Tivorsan, UCB, and Wave Therapeutics. He has research collaborations with Ultragenyx and Sanofi Genzyme. Volker also made a Personal non-pecuniary interest as he has been the chief/principal investigator for trials sponsored by Avexis, Genzyme, GSK, Prosensa/Biomarin, Ionis Pharmaceuticals, Italfarmaco, Pfizer, Sarepta and Summit and a sub-investigator for many other commercial studies.
  1. Part 2a – Closed session committee members, experts, ERG & company remained. (members of the public were asked to leave the meeting).
     1. The committee discussed confidential information submitted for this item.
  2. Part 2b – Closed session (company representatives, professional experts, external group representatives and members of the public 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 April 2021 and will start promptly at 9:30am.