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:** 8 October 2020

**Location:** via zoom

# Committee members present

1. Peter Jackson (Chair) Present for all items
2. Paul Arundel (Vice Chair) Present for all items
3. Ron Akehurst Present for all items
4. Sotiris Antoniou Present for all items
5. Philip Beales Present for all items
6. Sarah Davis Present for all items
7. Stuart Davies Present for all items
8. Carrie Gardener Present for all items
9. Jeremy Manuel Present for all items
10. Shela Mohammed Present for all items
11. Mark Sheehan Present for all items
12. Mark Smith Present for all items
13. Lesley Stuart Present for all items

# Committee Member Apologies:

1. Francis Pang – Conflicted

# NICE staff present:

Nicole Elliott, Associate Director Present for all items

Joanne Ekeledo, Project Manager Present for all items

Emily EatonTurner, Technical Advisor Present for all items

Alan Moore, Technical Analyst Present for all items

Sandra Robinson, Coordinator (MIP) Present for items 1 to 4.5

Cathryn Pank, Coordinator (MIP) Present for items 1 to 4.5

Sophie McHugh, Administrator Present for all items

Heidi Livingstone, Public Involvement Advisor (PIP) Present for all items

Laura Marsden, Public Involvement Advisor (PIP) Present for all items

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# External group representatives present:

Steve Edwards,BMJ Group Present for items 1 to 4.5

Samantha Barton, BMJ Group Present for items 1 to 4.5

Tracey Jhita, BMJ Group Present for items 1 to 4.5

# Professional experts present:

Ayesha Ali, NHSE commissioning expert Present for items 1 to 4.5

Fiona Marley, NHSE commissioning expert Present for items 1 to 4.5

Adnan Manzur, Clinical Expert, Novartis Gene Therapies Present for items 1 to 4.5

Volker Straub, Clinical Expert, Novartis Gene Therapies Present for items 1 to 4.5

Liz Ryburn, Patient Expert, SMA UK Present for items 1 to 4.5

Umut Izgi, Patient Expert, SMA UK Present for items 1 to 4.5

Gennadiy Ilyashenko, Patient Expert, Treat SMA Present for items 1 to 4.5

Charlotte Burfitt, Patient Expert,The Annabelle Rose Foundation Present for items 1 to 4.5

# NICE observers present:`

Helen Barnett, Senior Medical Editor Present for all items

Thomas Strong, HTA Adviser Present for all items

Alex Filby, HTA Adviser Present for all items

Cara Gibbons, Assistant HTA Analyst Present for all items

Emanuelle Kalten, French HTA (HAS) Present for all items

Henri Marfin, French HTA (HAS) Present for all items

1. Introduction to the meeting
   1. The chair welcomed members of the committee and other attendees present to the meeting.
2. Evaluation of Onasemnogene abeparvovec for treating type 1 spinal muscular atrophy [ID1473]
   1. Part 1 – Open session

4.1.1 The chair welcomed the invited professional experts, external group representatives, members of the public and company representatives from AbbVie

4.1.2 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.

* Adnan Manzur declared Direct personal Interests as he has done consulting work for Biogen: “SMA Expert questionnaire and advisory board” which took place in July 2017.
* It was agreed that his declaration would not prevent Adnan from participating in this section of the meeting
* Volker Straub declared a Financial interest as he received speaker honoraria from Sanofi Genzyme. He has or is currently on 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 also had research collaborations with Ultragenyx and Sanofi Genzyme.
* It was agreed that his declaration would not prevent Volker from participating in this section of the meeting

***No further conflicts of interest were declared for this item.***

* 1. The Chair introduced the lead team who gave presentations on the clinical effectiveness and cost effectiveness of the treatment.

4.3 The Chair asked the company representatives whether they wished to comment on any matters of factual accuracy.

4.5 Part 2 - Closed session (company representatives, professional experts, external group representatives and members of the public were asked to leave the meeting)

1. Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Wednesday 11 November 2021 and will start promptly at 9:00am.