NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:**  Confirmed

**Date:**  Thursday 07 November 2024

**Location:**  Via Zoom

## Attendees

Committee members present

1. Professor Iolo Doull (Chair) Present for all items
2. Annett Blochberger Present for all items
3. Emtiyaz Chowdhury Present for all items
4. Carrie Gardner Present for all items
5. Tina Garvey Present for all items
6. Professor Dusko Ilic Present for all items
7. Stuart Mealing Present for all items
8. Dr Shehla Mohammed Present for all items
9. Sara Payne Present for all items

NICE staff (key players) present

Richard Diaz, Associate Director  Present for all items

Vonda Murray, Project Manager Present for all items

Eleanor Donegan, Health Technology Assessment Adviser Items 1 to 4.3.2

Yelan Guo, Health Technology Assessment Adviser Items 5 to 5.4.2

Raphael Egbu, Health Technology Assessment Analyst Items 1 to 4.3.2

Emma McCarthy, Health Technology Assessment Analyst Items 5 to 5.4.2

External assessment group representatives present

Ollie Hale, Peninsula Technology Assessment Group, University of Exeter (PenTAG), Items 1 to 4.1.3

Liza Squires, Peninsula Technology Assessment Group, University of Exeter (PenTAG), Items 1 to 4.1.3

Ed Wilson, Peninsula Technology Assessment Group, University of Exeter (PenTAG), Items 5 to 5.2.3

Caroline Farmer, Peninsula Technology Assessment Group, University of Exeter (PenTAG), Items 5 to 5.2.3

Clinical, Patient & NHS England experts present

Bernd Schwahn, Consultant Clinical Paediatrician in Inherited Metabolic Medicine, clinical expert, nominated by Metabolic Support UK, Items 1 to 4.1.3

Laura Smith van Carroll, Head of Insight & Advocacy, patient expert, nominated by Metabolic Support UK, Items 1 to 4.1.3

Srividya Sreekantam, Consultant in Paediatric Clinical IMD, clinical expert, nominated by Birmingham Women’s and Children’s NHSFT, Items 1 to 4.1.3

Simon Jones, Consultant Paediatric inherited metabolic disease - clinical expert, nominated by NPUK, Items 5 to 5.2.3

Robin Lachmann, Consultant in Inherited Metabolic Disease clinical expert, nominated by Sanofi, Items 5 to 5.2.3

Toni Mathieson, Patient expert, nominated by NPUK, Items 5 to 5.2.3

Patient Carer Expert, Patient expert, nominated by NPUK, Items 5 to 5.2.3

James Dyson, Patient expert, nominated by NPUK, Items 5 to 5.2.3

Ayesha Ali, Medical Adviser for Highly Specialised Services at NHS England – commissioning expert, Items 5 to 5.2.3

*Please note that alongside the attendees listed in this document, there were additional NICE Staff present in this meeting. These attendees were not involved in the decision making or discussions.*

## Minutes

### Introduction to the meeting

* 1. The chair Professor Iolo Doull welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted apologies from Dr Paul Arundel, Angharad Shambler, Professor Jonathan Ives and Professor Ed Wilson.

### News and announcements

* 1. None.

### Evaluation of fosdenopterin for treating molybdenum cofactor deficiency type A [ID6264] (ECM2)

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Sentynl Therapeutics.
     2. The chair asked all committee members and experts, external assessment group representatives and NICE staff present to declare any relevant interests in relation to the item being considered. Declarations for this appraisal can be found on the Topic Register of Interest (TROI) on the topic webpage, [here](https://www.nice.org.uk/guidance/indevelopment/gid-hst10055/documents).
     3. The Chair led a discussion of the consultation comments presented to the committee.
  2. Part 2 – Closed session (company representatives, experts, external assessment group representatives and members of the public were asked to leave the meeting)
     1. The committee then agreed on the content of the Draft Guidance (DG) or Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Draft Guidance (DG) or Final Draft Guidance (FDG) in line with their decisions.
* Further updates will be available on the topic webpage in due course: <https://www.nice.org.uk/guidance/indevelopment/gid-hst10055>

### Appraisal of olipudase alfa for treating Niemann-Pick disease types A and B [ID3913] (ACM3)

* 1. Part 1 – Open session
  2. The chair Professor Iolo Doull noted apologies from Dr Paul Arundel, Angharad Shambler, Professor Jonathan Ives and Professor Ed Wilson who is attending as EAG representative for this topic.
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Sanofi.
     2. The chair asked all committee members and experts, external assessment group representatives and NICE staff present to declare any relevant interests in relation to the item being considered. Declarations for this appraisal can be found on the Topic Register of Interest (TROI) on the topic webpage, [here](https://www.nice.org.uk/guidance/indevelopment/gid-hst10060/documents).
     3. The Chair led a discussion of the consultation comments presented to the committee.
  3. Part 2 – Closed session (company representatives, experts, external assessment group representatives and members of the public were asked to leave the meeting)
     1. The committee then agreed on the content of the Draft Guidance (DG) or Final Draft Guidance (FDG). The committee decision was reached by consensus.
     2. The committee asked the NICE technical team to prepare the Draft Guidance (DG) or Final Draft Guidance (FDG) in line with their decisions.
* Further updates will be available on the topic webpage in due course: <https://www.nice.org.uk/guidance/indevelopment/gid-hst10060>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Wednesday 11 December 2024 and will start promptly at 9am.