NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Thursday 15 August 2024

**Location:** Manchester NICE Office/Zoom (hybrid)

## Attendees

Committee members present

1. Dr Paul Arundel (Chair) Present for all items
2. Professor Iolo Doull (Vice Chair) Present for all items
3. Emtiyaz Chowdhury Items 1 to 4.3.2
4. Sarah Davis Present for all items
5. Carrie Gardner Present for all items
6. Tina Garvey Items 1 to 4.3.2
7. Stuart Mealing Present for all items
8. Dr Shehla Mohammed Items 1 to 4.3.2
9. Sara Payne Present for all items
10. Angharad Shambler Present for all items
11. Professor Ed Wilson Present for all items
12. Professor Dusko Ilic (Observing) Present for all items

NICE staff (key players) present

Jacoline Bouvy, Programme Director, Medicines Evaluation Items 1 to 4.3.2

Jasdeep Hayre, Associate Director Items 1 to 4.3.2

Richard Diaz, Associate Director Items 5 to 5.2.2

Celia Mayers, Project Manager Items 1 to 4.3.2

Vonda Murray, Project Manager Items 5 to 5.2.2

Chris Griffiths, Health Technology Assessment Adviser Items 1 to 4.3.2

Alan Moore, Health Technology Assessment Adviser Items 5 to 5.2.2

Raphael Egbu, Health Technology Assessment Analyst Items 1 to 4.3.2

Zain Hussain, Health Technology Assessment Analyst Items 5 to 5.2.2

External assessment group representatives present

Ollie Hale, PenTAG Items 1 to 4.2.1

Ash Bullement, PenTAG Items 1 to 4.2.1

Matthew Stevenson, SCHARR Items 5 to 5.1.3

Sue Harnan, SCHARR Items 5 to 5.1.3

Clinical, Patient & NHS England experts present

Laura Smith van Carroll, Head of Insight & Advocacy, patient expert nominated by Metabolic Support UK Items 1 to 4.1.3 & Items 5 to 5.1.3

Ayesha Ali, Medical Advisor, Highly Specialised Services, NHS England Present for all items

Sanjeev Patel, IMF clinical lead, NHS England Items 1 to 4.3.2

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

Lucy Durrant, Parent, patient expert nominated by Metabolic Support UK Items 1 to 4.1.3

Zafar Aslam, Finance Advisor, patient expert nominated by Metabolic Support UK Items 5 to 5.1.3

Arunabha Ghosh, Consultant in Paediatric Inherited Metabolic Disease, clinical expert nominated by Metabolic Support UK Items 5 to 5.1.3

Reena Sharma, Consultant Adult Metabolic Medicine, clinical expert nominated by,Immedica Pharma UK, and Metabolic Support UK Items 5 to 5.1.3

Joan Ward, Medical Advisor, Highly Specialised Services, NHS England Items 5 to 5.2.2

*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, Dr Paul Arundel welcomed members of the committee and other attendees present to the meeting.
  2. The Chair noted apologies from Professor Jonathan Ives.

### News and announcements

* 1. None.

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Wednesday 12 June 2024.

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

* 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).
     3. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Dr Paul Arundel, Emtiyaz Chowdhury, and Angharad Shambler.
  2. Part 2a – Closed session (company representatives, clinical and patient experts, and members of the public were asked to leave the meeting).
     1. The committee discussed confidential information submitted for this item.
  3. Part 2b – Closed session (external assessment groups 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>

### Evaluation of pegzilarginase for treating arginase-1 deficiency [ID4029]

* 1. Part 1 – Open session
     1. The Chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Immedica.
     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-hst10054).
     3. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Dr Paul Arundel, Professor Iolo Doull, and Stuart Mealing.
  2. Part 2 – Closed session (company representatives, clinical and patient 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-hst10054>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 5 September 2024 and will start promptly at 09:00am.