NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Health Technology Evaluation

# Highly Specialised Technologies Evaluation Committee (HSTEC) meeting minutes

**Minutes:** Confirmed

**Date:** Wednesday 10 May 2023

**Location:** Via Zoom

## Attendees

Committee members present

1. Dr Peter Jackson (Chair) Present for all items
2. Dr Paul Arundel (Vice Chair) Present for all items
3. Annett Blochberger Present for all items
4. Emtiyaz Chowdhury Present for all items
5. Stuart Davies Present for all items
6. Sarah Davis Present for all items
7. Carrie Gardner Present for all items
8. Tina Garvey Present for all items
9. Professor Jonathan Ives Present for all items
10. Stuart Mealing Present for all items
11. Sara Payne Present for all items
12. Angharad Shambler Present for all items
13. Professor Ed Wilson Present for all items

NICE staff (key players) present

Richard Diaz, Associate Director Present for all items

Daniel Davies, Project Manager Present for all items

Alan Moore, Health Technology Assessment Adviser Present for all items

Summaya Mohammad, Health Technology Assessment Analyst Present for all items

Jacoline Bouvy, Programme Director Present for all items

External assessment group representatives present

Gurdeep Sagoo, Newcastle University Technology Assessment Review Group, Items 1.1 to 4.1.3

Hosein Shabaninejad, Newcastle University Technology Assessment Review Group, Items 1.1 to 4.1.3

Clinical, Patient & NHS England experts present

Lee-Ann Lorimer, Patient expert, nominated by MPS Society Items 1.1 to 4.1.3

Sophie Thomas, Patient expert, nominated by MPS Society Items 1.1 to 4.1.3

Dr Simon Jones, Clinical expert, Consultant Paediatric Inherited Metabolic Disease, nominated by company and MPS Society Items 1.1 to 4.1.3

Dr Suresh Vijay, Clinical expert, Consultant Paediatric Inherited Metabolic Disorders, nominated by company Items 1.1 to 4.1.3

Dr Ayesha Ali, NHS England, Medical Advisor to Highly Specialised Services, Items 1.1 to 4.1.3

*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, Dr Peter Jackson, welcomed members of the committee and other attendees present to the meeting.
  2. The chair noted apologies from Dr Shehla Mohammed, Anthony Williams and Philip Beales.

### News and announcements

* 1. None

### Minutes from the last meeting

* 1. The committee approved the minutes of the committee meeting held on Wednesday 15 March 2023

### Evaluation of Sebelipase alfa for treating Wolman disease [ID3995]

* 1. Part 1 – Open session
     1. The chair welcomed the invited experts, external assessment group representatives, members of the public and company representatives from Alexion Pharma UK
     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-hst10047)
     3. The Chair led a discussion of the evidence presented to the committee. This information was presented to the committee by Carrie Gardner, Sara Payne and Emtiyaz Chowdhury.
  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 through a vote by members.
     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-hst10047>

### Date of the next meeting

The next meeting of the Highly Specialised Technologies Evaluation Committee (HSTEC) will be held on Thursday 8 June 2023 and will start promptly at 9:00am.